

NOTE

This Microfiche meets the quality requirements of the American National Standard for Microfiche of Documents (ANSI PH5.9-1975). However, because of imperfections in the document from which it was made, it contains images that are illegible or difficult to read. The source document for this microfiche is the best copy that could be obtained prior to filming.



Congressional Information Service, Inc.
Washington, D.C.

CARING FOR AMERICA'S ALZHEIMER'S VICTIMS

HEARING BEFORE THE SELECT COMMITTEE ON AGING HOUSE OF REPRESENTATIVES

NINETY-NINTH CONGRESS

FIRST SESSION

MAY 21, 1985

Printed for the use of the Select Committee on Aging

Comm. Pub. No. 99-521



U.S. GOVERNMENT PRINTING OFFICE

49-922 O

WASHINGTON : 1985

H141-3

SELECT COMMITTEE ON AGING

EDWARD R. ROYBAL, California, *Chairman*

CLAUDE PEPPER, Florida
MARIO BIAGGI, New York
DON BONKER, Washington
THOMAS J. DOWNEY, New York
JAMES J. FLORIO, New Jersey
HAROLD E. FORD, Tennessee
WILLIAM J. HUGHES, New Jersey
MARILYN LLOYD, Tennessee
STAN LUNDINE, New York
MARY ROSE OAKAR, Ohio
THOMAS A. LUKEN, Ohio
BEVERLY B. BYRON, Maryland
DAN MICA, Florida
HENRY A. WAXMAN, California
MIKE SYNAR, Oklahoma
BUTLER DERRICK, South Carolina
BRUCE F. VENTO, Minnesota
BARNEY FRANK, Massachusetts
TOM LANTOS, California
RON WYDEN, Oregon
GEO. W. CROCKETT, Jr., Michigan
WILLIAM HILL BONER, Tennessee
IKE SKELTON, Missouri
DENNIS M. HERTEL, Michigan
ROBERT A. BORSKI, Pennsylvania
FREDERICK C. BOUCHER, Virginia
BEN ERDREICH, Alabama
BUDDY MacKAY, Florida
HARRY M. REID, Nevada
NORMAN SISISKY, Virginia
ROBERT E. WISE, Jr., West Virginia
BILL RICHARDSON, New Mexico
HAROLD L. VOLKMER, Missouri
BART GORDON, Tennessee
THOMAS J. MANTON, New York
TOMMY F. ROBINSON, Arkansas
RICHARD H. STALLINGS, Idaho

MATTHEW J. RINALDO, New Jersey,
Ranking Minority Member
JOHN PAUL HAMMERSCHMIDT, Arkansas
RALPH REGULA, Ohio
NORMAN D. SHUMWAY, California
OLYMPIA J. SNOWE, Maine
JAMES M. JEFFORDS, Vermont
THOMAS J. TAUKE, Iowa
GEORGE C. WORTLEY, New York
JIM COURTER, New Jersey
CLAUDINE SCHNEIDER, Rhode Island
THOMAS J. RIDGE, Pennsylvania
JOHN McCain, Arizona
GEORGE W. GEKAS, Pennsylvania
MARK D. SILJANDER, Michigan
CHRISTOPHER H. SMITH, New Jersey
SHERWOOD L. BOEHLERT, New York
JIM SAXTON, New Jersey
HELEN DELICH BENTLEY, Maryland
JIM LIGHTFOOT, Iowa
HARRIS W. FAWELL, Illinois
JAN MEYERS, Kansas
BEN BLAZ, Guam
PATRICK L. SWINDALL, Georgia
PAUL B. HENRY, Michigan
JIM KOILBE, Arizona
BILL SCHUETTE, Michigan

JORGE J. LAMBRINOS, *Staff Director*
PAUL SCHLEGEL, *Minority Staff Director*

CONTENTS

MEMBERS OPENING STATEMENTS

	Page
Chairman Edward R. Roybal	1
Matthew J. Rinaldo	2
Ron Wyden	3
Olympia J. Snowe	3
Mario Biaggi	5
Thomas J. Manton	6
Richard H. Stallings	6
John Paul Hammerschmidt	7
Tom Tauke	8
Michael Bilirakis	39

CHRONOLOGICAL LIST OF WITNESSES

Maria O'Brien, board member, Alzheimer's Disease and Related Disorders Association (ADRDA), Los Angeles, CA	9
James Strong, president, local Alzheimer's Disease and Related Disorders Association (ADRDA) Chapter, Oakland, CA	10
Kenneth R. Plum, member, Virginia House of Delegates, representing the National Conference of State Legislatures	19
Burton Reifler, M.D., director, Alzheimer's Clinical Research Center, University of Washington, Seattle, WA	21
Nancy L. Mace, M.A., board member of Alzheimer's Disease and Related Disorders Association (ADRDA), and, member, Maryland Task Force for Alzheimer's Disease	27
Richard Lamden, executive director, Handmaker Jewish Geriatric Center; and vice president, American Association of Homes for the Aged, Tucson, AZ	45

APPENDIX

Appendix 1. Summary of H.R. 2280: Comprehensive Alzheimer's Assistance, Research, and Education Act of 1985 (CARE), submitted for the record by Chairman Edward R. Roybal	53
Appendix 2. Additional material received for the record:	
Hon. Arthur S. Flemming, on behalf of the American Psychological Association, prepared statement	55
Hon. Margaret M. Heckler, Secretary, Department of Health and Human Services, prepared statement	56
Hon. James R. Thompson, Governor, State of Illinois, prepared statement	59

(III)

H141-3

CARING FOR AMERICA'S ALZHEIMER'S VICTIMS

TUESDAY, MAY 21, 1985

HOUSE OF REPRESENTATIVES,
SELECT COMMITTEE ON AGING,
Washington, DC.

The committee met, pursuant to notice, at 1:30 p.m., in room 2212, Rayburn House Office Building, Hon. Edward R. Roybal (chairman of the committee) presiding.

Members present: Representatives Roybal, Byron, Synar, Wyden, Sisisky, Wise, Robinson, Rinaldo, Snowe, Courter, Ridge, Saxton, Lightfoot, and Schuette.

Also present: Representative Bilirakis.

Staff present: Jorge J. Lambrinos, staff director; Gary Christopherson, health specialist; Nancy Smith, health professional staff; Austin Hogan, press secretary; Christinia A. Mendoza, executive assistant; Carolyn Griffith, staff assistant; Paul Schlegel, minority staff director; and Anne Riser, minority executive secretary/research assistant.

OPENING STATEMENT OF CHAIRMAN EDWARD R. ROYBAL

The CHAIRMAN. Ladies and gentlemen, the hearing will come to order.

Today the committee is holding this hearing to gather testimony on what the Federal Government should do to help America's 2.5 million Alzheimer's victims and their families.

How to care for the victims of Alzheimer's disease and related disorders is an important issue just because so many people suffer from these diseases. The issue becomes even more important when you consider that the cost of their care to families and the Nation is more than \$20 billion annually. Though the financial cost is great, the greatest tragedy is still the human cost for the victims and their families.

This afternoon we will receive testimony from those who most immediately suffer from the pain of caring for a father, a mother, or a spouse who suffers from these dreaded diseases. Every day these family members deserve our deepest respect and appreciation for having shouldered this heavy burden. Today they deserve our admiration again as they share their experiences in caring for a family member afflicted by these deadly diseases.

The Congress, I believe, must go beyond simply understanding this enormous tragedy and must take immediate, additional action. For this reason, we will be asking these family members, as well as other witnesses, to draw from their personal experiences and tell us what Federal, State, and local governments should do to help.

I am convinced that Alzheimer's is an exceptional disease which requires exceptional handling by the Congress this year. In 1985, we are spending only \$43 million on Alzheimer's related research. With the exception of Medicaid, virtually nothing is being done to help the victim or the families. Though this is becoming known as the year of budget cuts, Alzheimer's disease clearly demands special attention. In my own CARE bill, H.R. 2280, I am proposing a substantial step forward in funding for research and a beginning step in support for the families.

Next year, we must launch another and much greater attack on these diseases and the catastrophes that they cause. It is my intention to develop and push a larger, comprehensive bill in partnership with the Alzheimer's families, the practitioners and researchers, and State and Federal Government officials.

The question we will tackle this afternoon is, "What should the Federal Government do and what funding will be needed to help the victims of Alzheimer's disease?"

This may sound like a very simple question, but it is a question that requires a lot of thinking, a lot of compassion, and one that requires the coordination of State and Federal governments.

This afternoon we are asking the families of some of these patients who are victims to tell us of their personal experience. I personally would like to thank them beforehand for being here this afternoon. I realize it is not an easy task. But without your testimony, this committee, or any other committee of the Congress, would not be able to do anything at all. So, we thank you for your help and for your interest.

The Chair now recognizes Mr. Rinaldo.

STATEMENT OF REPRESENTATIVE MATTHEW J. RINALDO

Mr. RINALDO. Thank you, Mr. Chairman.

I want to commend you for convening this hearing today. Alzheimer's disease is only beginning to get the national attention that it deserves. Nine years ago, Federal research into Alzheimer's disease totaled less than \$4 million. Yet, this disease afflicts approximately 2 million individuals, and the cost of caring for Alzheimer's victims today is estimated to approach \$30 billion. Moreover, Alzheimer's accounts for an estimated 50 percent of the Nation's 1.3 million nursing home patients.

Mr. Chairman, I cannot think of any issue now before Congress which demands our attention more. Alzheimer's is a terrible disease, which takes away the victim's dignity and subjects his or her family to tremendous stress. We need to do more. Despite the demands of the budget and the pressures to reduce the deficit, I think we can do more. Unfortunately, the administration has put off for another year the establishment of two additional regional centers of excellence to study Alzheimer's. I think that we ought to push ahead with these centers as planned.

This hearing comes at an important time in the budget cycle. I hope it will help all the members of this committee to gain a perspective on an extremely crucial issue.

I want to thank you, Mr. Chairman, once again, and request unanimous consent that every member of this committee can have up to 5 days to submit a statement for the record.

The CHAIRMAN. Without objection, that will be the order.

The Chair now recognizes Mr. Wyden.

STATEMENT OF REPRESENTATIVE RON WYDEN

Mr. WYDEN. Thank you very much, Mr. Chairman.

I, too, want to praise you for holding this hearing. Alzheimer's is paralyzing millions of Americans, but it is also paralyzing the families who simply don't have the resources to cope with the huge medical bills that are incurred.

I particularly appreciate the comments of the gentleman from New Jersey because I think it is clear that the administration is not moving ahead vigorously to get at the causes and the cures of Alzheimer's. For example, only 7 Alzheimer's research grants are included in the 150 total grants funded by the National Institutes of Aging. I think that is less than the kind of committed, full-scale effort that we need in this country to get at this problem. I suspect that the real hangup is the Office of Management and Budget which always seems to believe that a cutback in an approved program such as the Alzheimer's really will save us money. In fact, what it usually does is cost us more money. The medical bills roll in because we haven't been able to find the cause and the cure for the problem.

I appreciate your holding this hearing, Mr. Chairman. I am happy to be part of this effort.

The CHAIRMAN. The Chair recognizes Ms. Snowe.

STATEMENT OF REPRESENTATIVE OLYMPIA J. SNOWE

Ms. SNOWE. Thank you, Mr. Chairman.

I wanted to say at the outset that I apologize that I will have to leave early because I have to testify before the Rules Committee concerning the budget.

Alzheimer's disease has been an issue of great concern to me for some time. I want to commend you, Mr. Chairman, for holding this hearing today to further examine the status of research on Alzheimer's disease and also the difficulties that are faced by the victims and the victims' families.

We know that 3 to 4 million Americans are afflicted with Alzheimer's disease, and I think we should include the family members in that statistic as well because they must deal firsthand with the effects of Alzheimer's and the long-term debilitating nature of that disease.

Six years ago when I first came to the Congress, there was not a single bill introduced on Alzheimer's. By the 98th Congress, we had more than 26 bills introduced in the Congress, and in this Congress there are 18 bills which have already been introduced addressing Alzheimer's disease. I think this is an indication of the growing awareness on the part of Congress that we need to address this issue, and we must grapple with our role in dealing effectively with Alzheimer's in the short term as well as the long term.

Clearly, our role can be designed to promote research to assure care for victims as well as encouraging the support for the victims' families.

In line with these goals, I introduced a number of bills in the last Congress as well as in this Congress. In the last Congress, I introduced several bills that were included as amendments to the Older Americans Act which gave priority consideration to those elderly Americans afflicted with Alzheimer's as well as priority consideration to grants for students who indicate that they will specialize in the area of Alzheimer's disease.

Finally, in this Congress, I have introduced legislation that will address policy within the Veterans' Administration to help those veterans afflicted with Alzheimer's.

In addition to that, I have introduced three bills with respect to supporting the families and financing the cost of assisting Alzheimer's victims. Toward that end I have introduced a bill that would provide a refundable tax credit of up to \$1,200. I have introduced legislation that would allow for deductions in our Tax Code for expenses other than medical costs to assist families as they are providing for Alzheimer's victims.

We all know the tragedy involved in this disease and the long-term concerns and burden that it places on the families.

So, again, Mr. Chairman, I thank you for holding these hearings. I think it is another indication of our resolve to address this issue. Hopefully, this Congress will go beyond words and address this issue through legislation that will assist those who are afflicted with this dreadful disease.

Thank you, Mr. Chairman.

[The prepared statement of Ms. Snowe follows:]

PREPARED STATEMENT OF REPRESENTATIVE OLYMPIA J. SNOWE

Thank you, Mr. Chairman, it is a pleasure to take part in these hearings which deal with a subject that has been of great concern to me for some time. My awareness and active support of the issues relating to Alzheimer's disease has developed from a recognition of the pain and suffering of the victim, and the equally poignant suffering of the family. While 3-4 million older persons are estimated to have Alzheimer's disease, the number who are counting among the afflicted should rightfully include the family members who must deal first-hand with this disease. The effects of Alzheimer's are felt by all those who love and care for the sufferer and who helplessly must watch the progress of this terrible disease.

Six years ago when I first came to Congress, not a single bill has been introduced to deal with the problems of Alzheimer's. In the 97th Congress, only three bills were introduced. By the 98th Congress, the total number had climbed to 26. So far this year, 18 bills have been introduced. I believe this gives a strong indication of the growing awareness and concern of this body over Alzheimer's disease. As legislators, we have finally begun to grapple with our role in dealing with this affliction, to explore ways in which we can promote research, to assure care for victims, and to encourage support for their families.

In line with those goals, I have introduced a number of bills which would help both the victims and their caregivers. I was pleased to note that, following a bill I introduced to increase authorizations to the National Institutes of Health for research on Alzheimer's disease, the appropriations committee increased funding for basic research in this area. Also, as a result of that bill, Ms. Heckler established an interagency Task Force on Alzheimer's. In addition, amendments which I proposed to the Older Americans Act were adopted last year. These required that special consideration be given to providing assistance to older persons with Alzheimer's and related diseases and they gave priority to education grant proposals for students who study the custodial or skilled care of victims of Alzheimer's.

In the 98th and again in the 99th Congress I introduced legislation which would address the care of veterans who suffer from Alzheimer's and I intend to continue to pursue this legislative initiative. I also have just introduced legislation which addresses the need of the caregiver by providing a refundable credit for respite services for dependent adults.

In August of 1983, the Subcommittee on Human Services held hearings in my district in Bangor, Maine where we explored the link between acid rain and aluminum and Alzheimer's disease. In that hearing, the subcommittee learned of the plight of the families of the Alzheimer victim, the problems that occurred in diagnosing the disease, and the problems of service delivery to families and victims. That hearing presented a new way of looking at Alzheimer's disease—as a possible function of environmental factors.

I think it is fair to say that Alzheimer's disease has become a part of our legislative consciousness.

Finally, I want to call my colleagues' attention to a film that will be aired tonight which graphically displays a fictional representation of what each person with a family member suffering from Alzheimer's knows all too personally and painfully. We will see an actress portray a woman who becomes a victim of Alzheimer's disease. We will see the love, the anguish, the sorrow, and the frustration of the victim and the family.

I look forward to this hearing as an important step in furthering our resolve to support the families that suffer from this disease. With this goal in mind, I hope that Alzheimer's Disease will in time be one of those illnesses that is just a thing of the past.

I look forward to hearing from the witnesses this afternoon.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you.

It was the Chair's intention to make an opening statement followed by that of Mr. Rinaldo, the ranking minority member, and then to go on with the introduction of a film clip that is to be shown. Due to time restraints, we are going to ask those who have opening statements to either submit them for the record or wait until after the clip has been shown and then you will be given an opportunity to make those opening statements.

[The prepared statements of Representatives Mario Biaggi, Thomas J. Manton, Richard H. Stallings, John Paul Hammer-schmidt, and Tom Tauke follow:]

PREPARED STATEMENT OF REPRESENTATIVE MARIO BIAGGI

I commend the Chairman for calling this hearing to focus continued attention on this tragic health problem affecting our Nation's elderly.

Alzheimer's is a dreaded disease that is progressive and irreversible, and by our estimate, affects more than 2 million Americans. The disease inflicts immeasurable pain on family members as well as victims.

Respite services are critical for the well-being of those who care for the individuals who have Alzheimer's. In partial response to this need, under the Older Americans Act Amendments of 1984, we have begun to respond to this need. Under an amendment to the Act that I sponsored last year, on behalf of our colleague Olympia Snowe, special consideration is to be given to projects for the recruitment and training of personnel and volunteers to assist individuals suffering from Alzheimer's disease.

I am pleased to note that my own New York City Office for the Aging Alzheimer's Support Center has been a pioneer in this area and is one of the first area agencies in the Nation to provide services to families to help them cope with the day-to-day difficulties associated with Alzheimer's Disease. Nonetheless, more still needs to be done.

In addition to alleviating the suffering that is associated with this disease, new knowledge about Alzheimer's will enable us to drastically reduce our national health bill. The cost of treatment and health care for Alzheimer's disease patients is estimated at \$25 billion annually. Additional funds should now be devoted to discovering the cause of the disease. We want to avoid this tremendous dumping of resources at the problem after the damage has been done.

Programs such as those at the five Alzheimer's Disease Research Centers in the Nation should be implemented on a widespread basis. The Alzheimer's research facility at the Mt. Sinai Medical Center has both clinical and basic science programs. It is an exemplary inter-departmental effort that needs continued support and replication.

I support and have cosponsored legislation such as that proposed by my colleagues Congressman Roybal and Congresswoman Snowe, to expand both services for Alzheimer's victims and research pertaining to the disease. Until we eradicate the disease, we must provide people with assistance in coping with its impact. Once again, Mr. Chairman, I commend you for holding this hearing and look forward to the testimony.

PREPARED STATEMENT OF REPRESENTATIVE THOMAS J. MANTON

Mr. Chairman, I would first like to commend you for holding this important hearing today on caring for America's Alzheimer's victims. Over 2.5 million Americans suffer from Alzheimer's disease, yet we are only beginning to understand its causes and possible treatments. As more of America's population lives longer, we must begin to examine ways to help the victims of this terrible disease and their families. But we must also seek out ways to most effectively help the victims and their families today.

The Congress must begin to determine additional ways to help the victims and their families in terms of monetary and emotional support. It seems clear that we can do much more at the Federal level. Alzheimer's disease has recently been receiving some much deserved attention, but not enough is known about the disease, its causes, treatment or possible cures. The monetary impact on families is severe. Sometimes savings that have been built up over a lifetime are totally depleted during the course of the illness. It seems inadequate to only provide aid when such dire straits have been reached.

We must also further develop the most effective ways to educate the public, to reach out to victims and their families and learn more about ways to help victims and their families cope. Alzheimer's is a tragic disease which affects not only the victim, but the family. Comprehensive approaches are needed to address the entire situation.

Today, we will be hearing about the experiences of family members as well as the experiences and suggestions from service providers and concerned citizen groups. And we will be examining some approaches that have been adopted at the State level. These witnesses will be most helpful as at the Federal level try to determine what our response and actions should be in order to most effectively aid the victims of Alzheimer's disease and their families.

Again I would like to thank Chairman Roybal for calling this hearing today. I would also like to commend the chairman for his introduction of the Comprehensive Alzheimer's Assistance, Research and Education Act of 1985, of which I am pleased to be a cosponsor. I believe this legislation is an important first step in helping to alleviate some of the tragedy experienced by Alzheimer's victims and their families.

PREPARED STATEMENT OF REPRESENTATIVE RICHARD H. STALLINGS

Mr. Chairman, I would like to commend you for your efforts to focus public attention and resources on the problems experienced by Alzheimer's victims, as well as on the physical and emotional difficulties that families and friends face in caring for their loved ones.

Alzheimer's Disease, a surprisingly common brain disorder, affects more than one third of American families. And, as emphasized in the Committee's investigation, Alzheimer's Disease, many of the 2.5 million victims of this tragic disease live in small towns or rural areas. Support groups such as the Alzheimer's Disease and Related Disorders Association (ADRDA) are making great progress in a number of rural areas; however, in others, there is very little support or information available for victims or their families. For these people, respite care and support services seem remote and unattainable.

The families from rural communities and small towns face the same difficulties discussed by the families of Alzheimer's victims who testified before the Committee—they wish to keep the affected family member at home and to want to provide the best home care for as long as they possibly can. The love and dedication evidenced by these families is enormous, but they cannot always provide the care without outside support.

One of my constituents who is caring for her father recently summarized the frustration experienced by family members struggling to care for an Alzheimer's victim: "Dad responds well to love and patience, but now he is 100 percent dependent on us for all his needs. We hear there are some things that can help, but where do we find out about them? If we could only know about the resources that are currently available, it would be of great assistance to us as we try to give the care that he needs."

Comments such as this one focus on the need expressed most often by families in rural areas. They do not want to institutionalize their loved ones and they are willing to make enormous sacrifices to provide the necessary care for their loved ones to remain in their homes and with their families. Tragically, as the disease progresses, so do the responsibilities placed on the family.

It is imperative that we take the steps necessary to provide the desperately needed assistance to Alzheimer's victims and their families—public awareness needs to be heightened; research initiatives need to be expanded; networks to provide treatment and services need to be developed; and current federal policies need to be examined to encourage financial assistance to Alzheimer's patients.

To this end, I am pleased to add my voice in support of Chairman Roybal's bill, the Comprehensive Alzheimer's Assistance, Research and Education Act of 1985 (CARE). This legislation proposes to initiate joint federal and state efforts to develop services and policies to assist victims of Alzheimer's and their families; to establish a National Alzheimer's Education Program; to conduct Medicare and Medicaid Demonstration projects in an effort to ascertain better methods of providing financial assistance to victims; and, to develop a plan of Alzheimer's related research to be implemented through the National Institutes of Health, the National Institute on Aging, and the National Institute on Mental Health.

Alzheimer's Disease is robbing too many older citizens of years that could spent contributing their knowledge, skills, and experience to society. The CARE bill is an innovative first step in improving the resources available to Alzheimer's victims and their families, and I applaud the Chairman for his efforts.

PREPARED STATEMENT OF JOHN PAUL HAMMERSCHMIDT

Mr. Chairman, Dr. Lewis Thomas, a prominent medical researcher and writer at the Sloan-Kettering Institute, has called Alzheimer's the disease of this century. I believe his statement was referring to our recent recognition of the seriousness of the condition and the current surge of scientific research in this area. There is still so much to learn about Alzheimer's disease. We need to know how to improve its diagnosis, understand its clinical cause, find effective treatment modalities, and develop systems of care with appropriate financing mechanisms.

Health and Human Services Secretary, Margaret Heckler, has made Alzheimer's disease a high priority and established a Department Task Force on Alzheimer's Disease in April 1983. The goals of the task force were to consolidate current research, to identify the most promising types of research and, most importantly, to provide a means of translating that research into policy and programs to improve the quality of life for older Americans.

In the United States today, the number of older persons with Alzheimer's disease is estimated at 1.5-2.5 million. However, the incidence of Alzheimer's is projected to increase significantly as "one-third of the entire population in the developed countries will survive to at least 80 years of age when the risk of having Alzheimer's disease increases to about 20 percent." Therefore, even if we see no increase in incidence, the absolute number of cases will increase as the number of persons surviving to old age increases.

Mr. Chairman, I think it's important that today's hearing focuses not only on research but on the care that is required by Alzheimer's patients. And, it appears that a significant portion of Alzheimer's patients receive care at home provided by their family members. It has been said that no other disease causes more damage to the family than Alzheimer's. Beside the stress of caring for a loved one who is mentally, physically, and emotionally deteriorating, families are hampered by the lack of adequate medical reimbursement and a limited community-based health and social services.

I hope that one of the consequences of this hearing will be our renewed effort to develop public services for those families who provide the primary care in the community, and not force them to institutionalize family members to obtain necessary assistance. I look forward to hearing the testimony of our distinguished witnesses so that those of us in Congress can better understand the effects of this terrible dis-

ease, and can evaluate, and if necessary, change the policies which affect the care of Alzheimer's patients.

PREPARED STATEMENT OF REPRESENTATIVE TOM TAUKE

Mr. Chairman, I am honored to join you as a cosponsor of your bill, H.R. 2280, as we examine the role of the Federal Government in the care of Alzheimer's disease victims and the support of their families. Formerly an unexamined problem, this tragic disease has now generated national concern. Today's hearing and the mounting congressional concern for the issue are responsive to the growing aging population of the United States and the increase in the understanding of the disease. A national partnership between government and medical institutions is needed to address the need for cooperation in medical research and education. The costs of medical and family support care have become economic burdens to society. More importantly, the emotional cost to victims and their families is immeasurable. I commend your leadership and the continued interest of the committee in all aspects of Alzheimer's disease. As the number of congressional hearings on this issue grows, so does public awareness of the problem. While congressional hearings are important vehicles of communication, legislative action is critical in the areas of research and patient care.

During the last Congress, the Aging Committee's Subcommittee on Health and Long Term Care and the Subcommittee on Health and the Environment of the Energy and Commerce Committee on which I serve held hearings on this issue.

The Senate Labor and Human Resources Subcommittee on Aging also held hearings during the last Congress. During those hearings Antonio R. Damasio, M.D., Ph.D., of the University of Iowa College of Medicine in Iowa City presented some interesting observations. He noted that there are many avenues necessary to increase our understanding of Alzheimer's disease. Our priorities should be to discover the mechanism of the disease to prevent it or block its progression. The solution to the degenerative dementia will come only through a major investigative effort in animals and humans. He shares the opinions of other scientists who feel our epidemiological knowledge is insufficient. Dr. Damasio also reports that we need to improve our clinical and neurological diagnosis to provide the earliest detection of the disease. His final recommendation is the essence of today's hearing: Maintenance of the social and medical support services that will be necessary to ease the suffering of patients and families. I believe that Chairman Roybal's legislation will address the need for medical research, training, public education and service delivery. However, we must continue to pursue adequate research funding for the causes, treatment and diagnosis of this disease. As a member of the Health Subcommittee of Energy and Commerce, I will be paying close attention to measures which maintain the excellent research efforts at the National Institutes of Health and programs to assist victims and their families.

The CHAIRMAN. In order to comply with the time that has been allotted to us by television, and so forth, I would like to take just a few minutes for all of us to view a brief clip of a film being aired tonight by CBS, and developed in cooperation with Alzheimer's Disease and Related Disorders Association. The film will be shown this evening, and it is called "Do You Remember Love." It is a very moving portrayal of the same kind of tragedy experienced by two of our witnesses that will be testifying this afternoon, Ms. O'Brien and Mr. Strong.

One special note is that Joanne Woodward who portrays Barbara in the film has personally felt the tragedy. Her mother suffers from Alzheimer's disease.

If we are ready now we will view the clip and then come back to the regular process.

[Film shown.]

The CHAIRMAN. May I recommend to each and every one of you that you see the film this evening. You will see it on CBS from 9 to 11 and I think we will be in for two very emotional hours.

I think we all know Alzheimer's disease is an enormous tragedy, and can touch anyone deeply and in every walk of life, rich, poor, regardless of color or religion. We must do everything we possibly can as legislators to try to lighten the burden.

I would like to now call the first witness, ladies and gentlemen. The witnesses today will be Ms. Maria O'Brien, Mr. James Strong, Mr. Kenneth Plum, Dr. Burton Reifler and Ms. Nancy L. Mace, and Richard Lamden. These are all men and women that are experts in the field and can personally relate to the overall problems of Alzheimer's disease.

Ms. O'Brien, will you please start off the discussion.

STATEMENT OF MARIA O'BRIEN, BOARD MEMBER, ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION [ADRDA], LOS ANGELES, CA

Ms. O'BRIEN. Happily, Mr. Chairman, and members of the committee. My name is Maria O'Brien and I am a board member of the Los Angeles ADRDA, the Alzheimer's Disease and Related Disorders Association.

Speaking as someone whose life has been touched by this horrible illness, I want to thank you for allowing me the opportunity to be here today. I also want to thank you and your colleagues for the compassion and leadership you have shown in the battle against Alzheimer's disease.

Mr. Chairman, I cannot begin to describe for you the tragic impact Alzheimer's disease has on an otherwise healthy, vibrant person. Nor can I explain the sorrow and feelings of helplessness one experiences at seeing a loved one suffer through the prolonged stages of this disease.

For me, Mr. Chairman, the fact that Alzheimer's disease will strike one out of every six parents has special meaning.

From the time he began to study his craft with Orson Welles to his Academy Award-winning performance in the "Barefoot Contessa," my father devoted his life to bringing entertainment to generations of moviegoers. What the public saw, of course, was an actor who was able to project his talents with the greatest skill and precision.

As his daughter, what I saw was his strength of character, his force of intelligence, and his generosity of purpose.

My father passed away a few days ago.

Like so many unfortunate victims of this disease, he had lost virtually all mental and neurological functions. Ironically, a man who once could hold an audience in the palm of his hand, toward the end, had great difficulty expressing even his most basic feelings of affection, recognition, and love.

In a very real sense, death was the only hope of release for my father.

Mr. Chairman, over the past several decades this country has made some pretty remarkable strides when it comes to ensuring the older generation the dignity and security that a lifetime of work deserves.

But as President Kennedy once said, "the last of life for which the first was made is still not a golden age for all our citizens."

That is certainly the case for the more than 2½ million people who have been stricken with Alzheimer's disease.

For the victims, like my father, instead of enjoying those golden years, this disease means years of disablement; for the families, it means years of hardship. Of course, as you know, Mr. Chairman, both the victims and their families usually end up suffering in silence—and with little help from anyone else.

Medical research is important, and we all encourage you to continue the strong Federal commitment to finding the answer to this mystery. But the fact remains that, today, families all over this country are involved in a desperate struggle to cope with the ravages of Alzheimer's disease.

Medicare does not cover the cost of caring for an Alzheimer's victim—either at home or in a nursing home. Even though my father was fortunate enough to be admitted to a VA hospital, more often than not these facilities are unable to accommodate Alzheimer's patients.

In other words, for the vast majority, the burden and the costs of providing around-the-clock care and supervision rests squarely on the family.

Mr. Chairman, I will leave it to the experts in this room, and I see there are many, to discuss the medical and scientific aspects of this problem. But for my part, I would just like to conclude by saying that this is a national problem, and it will take a national effort to solve it.

I think we all realize that these are difficult times, but I believe that legislation such as the bill which you recently introduced, represents a good start toward meeting the desperate needs of families across the country.

Again, thank you for allowing me the opportunity to be here today. I will be happy to answer any questions.

The CHAIRMAN. Thank you, Ms. O'Brien.

The Chair recognizes Mr. James Strong.

STATEMENT OF JAMES STRONG, PRESIDENT, LOCAL ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION [ADRDA] CHAPTER, OAKLAND, CA

Mr. STRONG. I am here to speak, Mr. Chairman, and members of the committee, as the son of an Alzheimer's patient. I brought my mom from Florida, where she had been living, back to California about a year ago and began caring for her and learning firsthand about Alzheimer's disease. Now she can get along in an independent living facility with a nurse's aide during the day and with a constantly changing regime of medication, she is able to have as close to a normal appearing life as I can manage for her.

I also am here to speak on behalf of the many people whose stories I have heard in support groups, meetings, and in seminars, people from around the country, all kinds of folks. I have in the last year also gone from reading my first book on Alzheimer's disease to becoming active in the Alzheimer's Disease and Related Disorders Association at the local, State, and national level.

I am the president of my local chapter of ADRDA, and I also serve on the board of a new State-funded Alzheimer's Diagnosis and Treatment Program.

The issue of research can seem like a dry and remote one, but not only does my mother have Alzheimer's disease, but also I believe does my aunt and did their brother, when he died. I know as well as anyone that there is no certainty about what that means for me in later life.

But I will tell you, it is a fear that I cannot reason beyond.

My wife is a very resourceful person but I cannot imagine what would happen to her if she had to deal with 5 to 10 years of a slow decline into helplessness by me.

I have a couple of kids, who by the grace of God come to me through my wife's previous marriage. Until the research pays off, I feel fortunate that I have borne no children of my own.

In about 25 years we baby boomers may well start our own Alzheimer's boom. We could go from 2½ million cases to 4 million cases by the year 2000. Twenty-five years is not a lot of time starting from the half dozen good approaches that have been developed so far, to find a cause, a diagnosis, a treatment, and a cure. I think that if my generation was educated by people like you about the long-term economic and demographic problems that challenge the ability of the baby boomers to have a secure retirement, they would see that it would make eminent good sense to fully research into Alzheimer's disease.

Right now what we spend on all research for Alzheimer's disease, what is being proposed, about \$43 million, is about 1/800 of the \$34 billion that are being spent on Alzheimer's, when you consider lost wages and direct expenses to the families, as well as nursing home costs.

I am told that of all that research, about \$10 million is basic research, the kind of research that could lead to a cure. So that comparison means that we are spending about 3,400 times as much on caring for our patients as we are in direct research that might lead toward a cure.

Now, unlimited funds aren't the answer. Dealing with this disease has emboldened me. So I called up Dr. Robert Katzman. He is the chairman of the Neurology Department at the University of California, San Diego, and also head of the Center for Excellence in Research in Alzheimer's disease there. I asked him how much research should be increased. He considered not only the pressing need but also the number of new researchers entering the field. He felt that the total research budget would be most effective if the \$43 million was increased by 35 percent this year. That would be a good balance between the available researchers, the cost of the new technologies, and the need.

While research is clearly important, there are millions of families out there, the people I have met, who are facing excruciating problems today, and they have got to be addressed. Right now, most of the Alzheimer's patients are being cared for by families and they want to do more. The thing that amazes me is how tough the families are, the caregivers. They go through years where they are seeing these unexplainable changes happen in their loved ones. They see good cooks forget how to prepare familiar dishes.

I remember when I went back to visit my mom and she served me dinner which was a bowl of split pea soup with strawberries in it, and a saucer of milk, and I ate it gladly. She could tell something was wrong, but she didn't know what. That kind of loss is very common and it is hard to accept. They have seen good workers lose their jobs, they have been physically and verbally abused by their mates. They have felt abandoned when their lifelong mates have forgotten their names.

They have spent their life savings down to the poverty level to pay for nursing homes that didn't provide the kind of care that would really take care of their patients. They have lost their own health taking care of their patients.

Alzheimer's patients typically wake up a lot during the night and like to get up and walk around. Unless you are going to risk serious fire hazard in your home, you cannot lock the doors in the way they cannot get out. You have to get up and be with them all during the night.

The really amazing thing is that these people come back and start family support groups so they can share their hard won knowledge with the next generation that has to deal with this disease.

I think it takes more heart to face another day of caring for an Alzheimer's patient than most of us need to come up in a year.

I want you to know that these people, as they are being worn down and impoverished, are nonetheless strong and resourceful individuals, they are the kind of partners you should be proud to have, and you can make an enormous difference in their lives with interventions that are modest compared to the total cost of care.

Awareness is critical. Not only does the public need to know but physicians need to know. My uncle declined through Alzheimer's without having any kind of dementia being diagnosed. My aunt had no idea why her husband of all those years was suddenly becoming abusive and suspicious. My cousins are about as well placed as you can imagine to be in the network that would let them know about Alzheimer's. I talked to them a while ago and they told me the doctor ruled out Alzheimer's disease, he said it was senility.

Well, for those of you who don't know, senility is no longer an accepted concept, it is not something that just happens. That is how that doctor was treating my aunt.

Services, even when people know to ask for them, are simply not available. Many breadwinners have to quit their jobs because there aren't services available and they then start heading for Federal support they don't want.

Divorce is often considered with great regret by the husbands and wives of Alzheimer's victims because of the financial burdens. They are forced to face the end of a relationship simply for financial reasons and I don't think they should have to.

The bill that has been introduced, a comprehensive Alzheimer's assistant research and education bill, addresses the kind of issues that I hear about in support groups. I urge you to work for its passage.

Thank you very much. I would like to make one additional request, and that is that a document that does a good job of summarizing the policies that might be pursued, "A National Program To

Conquer Alzheimer's Disease," prepared by the Alzheimer's Disease and Related Disorders Association, be introduced onto the record.

Mr. WYDEN [presiding]. Hearing no objection, that will be done.

[The prepared statement of James Strong and the aforementioned document referred to follow:]

PREPARED STATEMENT OF JAMES STRONG, PRESIDENT, LOCAL ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION [ADRDA] CHAPTER, OAKLAND, CA

My name is Jim Strong. I am here today to speak as the son of an Alzheimer's patient. A year ago, I moved my mother from Florida to California and began to care for her and to learn about Alzheimer's first hand.

I also seek to speak for the many Alzheimer's families I have met in support groups and seminars. In the last year I have gone from reading my first book on Alzheimer's to becoming active at the regional, state and national level in the Alzheimer's Disease and Related Disorders Association (ADRDA). I serve as President of the local ADRDA Chapter and on the board of a state funded Alzheimer's disease diagnosis and treatment center.

In my testimony, I will refer to people with Alzheimer's Disease. A caveat is in order. Even the most skilled diagnostician cannot identify this disease with certainty during life. That can only be done with an autopsy. In many cases a thorough diagnostic procedure has not been pursued and individuals may be suffering from any of a variety of disorders which produce similar symptoms. Thus the plight of many of the estimated 4 million Americans with dementia, including about 10% with reversible causes, ends up being indistinguishable from that of the estimated 2.5 million Americans with Alzheimer's disease.

RESEARCH

Depending on the success of research funded now, my generation "the baby boomers" may begin to generate their own Alzheimer's boom in about 25 years. There may be 4 million cases of Alzheimer's by the year 2000. Starting from the ½ dozen promising approaches researchers have developed so far, 25 years is not much time to determine the cause and to develop effective diagnostic methods, treatments, and a cure.

Care of our Alzheimer's patients now costs about \$34 billion a year. Until the results of successful research intervene, that figure will grow automatically as our population ages. It lies with you and your fellow Members of Congress to see that research funding increases at as rapid a pace as can the capacity of the research community to employ funds well.

Now we spend only 1/800 of the cost of care on research.

Dr. Robert Katzman, Professor and Chair of the Neurology Department and Head of the Center of Excellence at the University of California, San Diego, has weighed the serious impact of the disease and the number of qualified researchers who have entered the field. He recommends that the federal research effort would be most effective if increased 35% this year.

FAMILY AND PATIENT SERVICES

While full funding of research is critical in controlling the long term personal, family and societal cost of the disease, millions of families are facing excruciatingly difficult problems today.

The many families I have met do not want the federal government to take over the job of caring for their loved ones. Indeed, they want to do more. About 40% of Alzheimer's cases have advanced beyond the possibility of home care and are now in nursing homes. The families want to reduce that percentage and keep their patients home longer.

It is difficult to summarize the experiences of the families whose stories I have heard. Let me share with you some typical experiences of caregivers.

They have coped with unexplainable changes in loved ones, seeing good cooks forget how to prepare familiar dishes and anguished overproductive workers lose their jobs. They have been alone, uninformed and, what's worse, misinformed. They have been battered and verbally abused. They have felt abandoned as life-long mates forgot their names. They have learned to diaper their husbands and wives when they are incontinent. They have spent their life savings down to the poverty level in order to get Medicaid to pay for nursing home care that still did not provide

for the unique needs of Alzheimer's patients. They have lost their own health under the strain of 24-hour-a-day care-giving. They have felt guilt at their own relief when death finally ended years of slow decline. And even after all of this, they have come back to organize family support groups so they can share their hard won knowledge.

As Members of the House Select Committee on Aging you can make a powerful difference in the lives of millions of these courageous people with some modest interventions. You can make it possible for them to keep their patients home longer with less loss of the care-giver's health and the family's ability to remain financially independent.

Awareness

The public must learn the basic facts about the disease. One job our families do want you to take over is making sure that our family doctors are properly educated. Their level of knowledge is improving but we still hear a shocking number of stories about doctors diagnosing "senility" and seeming to dismiss the case as no longer of interest because it is untreatable.

Availability

Many breadwinners have had to leave their jobs for the sole reason that in-home and day care services, capable of dealing with their patients, was not available at any price.

Affordability

Once families get over the news that a loved one suffers from a disease with no certain diagnosis in life, no known cause, no treatment, and no cure, they still have more difficult news to handle. The prognosis for the family itself is very often poverty. There is no insurance no tax break, often no long term care in veterans hospitals, and often no affordable in-home or day care from programs capable of caring for Alzheimer's patients.

Ultimately, our society will share the cost of care by creating affordable insurance for long-term custodial care. This will require the collaboration of the insurance industry, businesses, unions, and citizens' groups. Perhaps this Committee can sponsor the initial dialogue which will lead to this needed cooperation.

CONCLUSION

The Comprehensive Alzheimer's Assistance, Research and Education Act of 1985 (CARE) addresses many of the needs I have heard expressed by families from all walks of life and from all over the country. I urge the members of this Committee to take the lead in passing this bill and funding these programs at a level which will allow us to conquer Alzheimer's Disease.

NATIONAL PROGRAM TO CONQUER ALZHEIMER'S DISEASE

(Prepared by the Alzheimer's Disease and Related Disorders Association)

"Given the threshold blessing of longer lives, the important question then becomes how healthy, active, and independent our older years will be. Even as the proliferation of medical miracles and ever improving health care have been major contributing factors in this ongoing transformation of our nation's 'profile', too many of our people still fall prey to serious illness. None is more terrifying and life altering for the elderly than Alzheimer's disease."—Margaret M. Heckler, Secretary, Department of Health and Human Services, September 1984.

I. STRENGTHENING SUPPORT FOR MEDICAL RESEARCH

"Recent advances in brain research have put us in the midst of the most exciting era since the dawn of the space age."—Michael Phelps, Ph.D.; UCLA, Wall Street Journal, 12/19/83.

Although significant advances have been made in understanding the working of the human brain, the cause of Alzheimer's disease is still elusive. New hypotheses are being vigorously tested in a growing number of investigations. These studies are focusing on etiological factors as diverse as chemical deficiencies, immune dysfunction, slow viruses and unconnected agents, toxins, trauma and genetic abnormalities.

The number of unanswered questions is so great that the federal government must play a substantial role in helping to mount a strong and sustained research

effort. The following areas are recommended as promising directions for future research:

Etiology and pathogenesis

Support and enlarge research in order to enhance understanding of the cause(s) of the progression of Alzheimer's disease. Such research would include attention to the etiological impact of chemical deficiencies in the brain, advancing chronological age, genetic abnormalities, atypical transmissible agents, environmental toxins and trace metals, autoimmune dysfunction, and psychosocial trauma and stressors.

Encourage existing brain tissue banks to include tissue from Alzheimer's disease patients and from age-matched controls; periodically review to ensure an adequate number of such facilities.

Develop animal models of Alzheimer's disease with more precise neuropathologic and biochemical correlates.

Diagnostics

Develop international standardized diagnostic research criteria.

Develop biological and/or behavioral markers for the early detection of Alzheimer's disease.

Undertake longitudinal studies in order to document in a systematic fashion the progression of the disease.

Examine cases of serious discrepancy between degree of cognitive deficit and extent of brain impairment.

Clinical course

Develop longitudinal assessment instruments capable of reliably measuring behavioral and biological change over multiple points in time.

Investigate factors that hasten or delay the progression of symptomatology.

Examine individual differences and variability in severity, rate of deterioration, duration of illness and capacity for self-care.

Treatment

Develop new treatment agents for the cognitive and other impairments of Alzheimer's disease.

Establish more sensitive measures of cognitive, affective, somatic, and other changes for use in drug outcome studies.

Evaluate the influence of the environment of Alzheimer's disease patients and collect information regarding the range of behavioral plasticity in patients at different stages of the disease.

Epidemiology

Develop standardized diagnostic assessment for Alzheimer's disease that are suitable for use in field studies.

Determine age-specific incidence and prevalence rates of Alzheimer's disease in diverse populations and study the course of illness.

Assess a variety of possible risk factors that may be associated with the development of Alzheimer's disease.

II. PROVIDING FAIR AND EQUITABLE CONSIDERATION UNDER FEDERAL DISABILITY PROGRAMS

The Social Security Administration has national responsibility for the administration of both the Social Security Disability Program (Title II) and the newer Supplemental Security Income Program, or SSI (Title XVI). Title II provides coverage for cash benefits to those disabled workers, and their dependents, who have contributed to the social security trust fund through the FICA tax on their earnings. These individuals have an earned right to disability insurance benefits. Title XVI provides for a minimum income level for the needy aged, blind, and disabled who qualify because of financial need rather than an earned right.

Under both programs, the definition of disability is the same—"an inability to engage in any substantial gainful activity by reason of a medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months." The determination as to whether or not an applicant is disabled as defined by law is made by a special disability determination unit in each state.

Current policy is vague

The statutes authorizing disability benefits do not preclude benefit payments to individuals suffering from Alzheimer's disease. However, the guidelines used by claims examiners to determine eligibility are somewhat vague when it comes to Alzheimer's disease and related disorders.

One very typical example of the problem involves a 58 year old woman who was diagnosed with Alzheimer's disease in 1980. Last year, she was denied disability benefits even though the Social Security Administration noted that she has "... some difficulty in concentrating and remembering and an inability to travel by herself."

The disease is not listed among those brain disorders specifically identified in the guidelines. At the present time a determination of disability due to Alzheimer's disease must be made under the "mental disorders" category. Unfortunately, the eligibility criteria under this category do not lend themselves to cases involving Alzheimer's disease. Furthermore, in some areas state laws prohibit the use of certain specific diagnostic tools needed to demonstrate deterioration in intellectual functioning.

The vagueness in regulations and guidelines has led to wide variations from state to state and an uneven policy towards individuals who have a rightful claim to benefits. In some states rulings have made it possible to determine most Alzheimer's patients are disabled, while in others, extremely strict rulings have made it almost impossible to find an Alzheimer' patient to be "significantly impaired".

Among other things, it seems apparent that the serious and debilitating nature of Alzheimer's disease—information that is so readily available to scientists and many physicians—is not being communicated to those who must make the critical, day-to-day eligibility determinations.

Recommendations

1. The federal regulations and guidelines used in evaluating disability claims should be amended so as to recognize the rights of individuals diagnosed as having Alzheimer's disease.
2. A mechanism should be established whereby the most current scientific information available to the National Institutes of Health and the National Institute of Mental Health is communicated to those responsible for administering disability programs.
3. Federal agencies, working together with medical and scientific community, should devise specific assessment tools that could be uniformly used by examining physicians.

III. MEETING LONG-TERM CARE NEEDS

Long-term care is a growing national concern. Yet, by and large, national public policy overlooks the most pressing needs of this segment of the population, including those individuals suffering from Alzheimer's disease.

The catastrophic costs of long-term care for Alzheimer's patients often are borne almost entirely by their families, since neither Medicare nor most private insurance plans provide coverage. Medicaid offers some assistance for nursing home costs, but only after families have spent down to poverty in order to qualify.

While the population of Alzheimer's patients is not exclusively aged (more than 60,000 victims are in their forties and fifties), the vast majority are over age 65 and in serious need of assistance, including—around-the-clock supervision, medical assistance, personal care (eating, bathing, dressing, toileting), mobility assistance, household assistance (meal preparation, housekeeping).

While most families are likely to encounter difficulties coping with long-term medical care costs, those difficulties are far more pronounced for the elderly. Most frequently, the long-term care needs of an Alzheimer's victim arise at a time when the family's economic and social resources are dwindling—oftentimes after savings, other assets, and pensions are nearly exhausted. Of course, the problems are particularly serious for the large number of victims who have no family or friends to care for them.

Compounding the problem for families is the fact that what little assistance is available is biased toward institutionalized care. The fact is that about two-thirds of the Alzheimer's victims with families are cared for in the home; only when the disease is in its final stages are families likely to turn to nursing homes for help. Even then, families of Alzheimer's victims are likely to encounter problems with access, as many nursing homes prefer short-stay, Medicare or privately insured patients.

Finally, the needs of families are virtually ignored by our system of social protections. No provision is made for the needs of the spouse who is caring for an Alzhei-

mer's victim, including home health care, adult day care, and periodic respite care to help fortify the health and well-being of the care give.

Given this myriad of problems, it is recommended that an integrated long-term continuum of care be provided for victims of Alzheimer's disease. Toward this end, the following actions are recommended:

Recommendations

1. Medicare coverage should be extended to cover the costs associated with caring (at home or in a nursing home) for victims of Alzheimer's disease.
2. Greater emphasis should be placed on research studies and demonstrations to explore alternative health care delivery for Alzheimer's victims.
3. Victims, families, and care givers should be afforded a full range of home care services, including adult day care, respite care, homemaker, and nutrition services. (See also Section IV, Provision of Respite Care Services.)
4. Families and care givers should be permitted a tax deduction or refundable tax credit for the special added costs associated with caring for an Alzheimer's victim at home. (See also Section V, Incentives for Home Care.)
5. Private insurers should be encouraged to develop reasonable cost insurance plans that cover Alzheimer's disease.

IV. PROVISION OF RESPITE CARE SERVICES TO FAMILIES

While most Alzheimer's families prefer to care for their loved one in the home, several studies¹ have reported on the problems experienced by the care giver; namely, emotional stress, loss of freedom, isolation, illness and financial strain. Given the demands for around-the-clock care and supervision, most family care givers are in desperate need of some relief, if only a chance to get away for a few hours.

Responding to the needs of the Alzheimer's families, Congress last year passed legislation which begins to address the issue of support services. Specifically, (a) the 1985 Labor-Health and Human Services Appropriations bill instructs the Administration on Aging to work with the Alzheimer's Disease and Related Disorders Association (ADRDA) and other groups in meeting local needs for respite care services, as well as develop a nationwide effort for providing respite; and (b) the Older Americans Act Amendments of 1984 sets aside funding to support local model projects to provide Alzheimer's disease families with a range of support services, including respite care, day care, and in-home health services.

Recommendation

1. That the Administration on Aging launch a nationwide effort to meet the respite care needs of Alzheimer's families, and that the Alzheimer's Disease and Related Disorders Association be invited to participate in this effort.
2. That the Administration on Aging, in fiscal year 1986, begin to carry out the mandate of the 1984 Amendments by funding local model projects for respite care, day care, and in-home services.

V. INCENTIVES FOR HOME CARE

The financial hardships of a family who has been touched by Alzheimer's disease is staggering. Around-the-clock care of an Alzheimer's victim can cost a family over \$30,000 per year. Many families virtually deplete their life savings, and eventually become dependent upon government programs for financial assistance.

The Alzheimer's Disease and Related Disorders Association believes that a national policy should be formulated which encourages families to care for their loved ones afflicted with Alzheimer's disease in the home. We find this to be the health care preference of a majority of our families. Moreover, such an approach offers a most effective way to reduce health care costs at the public level. (According to a 1984 analysis by the Education and Public Welfare Division of the Library of Congress, expenditures for nursing home costs are expected to grow from \$27.3 billion in 1982 to a level of \$67.1 billion by 1990.)

Recommendation

That families be allowed a tax deduction or refundable tax credit for expenses, other than medical expenses, incurred for the caring of Alzheimer's victims in the home.

¹ Archbold, 1982, 1981; Crossman, 1981; Fengler and Goodrich, 1979; Sanford 1975.

VI. ESTABLISHING A CONSISTENT POLICY TOWARDS VETERANS

The Veterans' Administration (VA) currently has no consistent policy with respect to veterans with Alzheimer's disease. This has resulted in uneven, some believe unfair, treatment of veterans. Some Victims of the disease are admitted to VA medical facilities, while others are denied admission or referred to other state or private agencies. In some instances, veterans are being forced to leave VA facilities or are being "out-placed", thereby disrupting their care and placing even greater strain on the family.

The problem threatens to become even more serious as far greater numbers of veterans enter the vulnerable over-65 age bracket. (At present there are 3.3 million veterans age 65 and over; by 1995, that segment of the population will grow to over 8 million.)

Recommendations

1. The Veteran's Administration should institute a fair and consistent national policy toward veterans with Alzheimer's disease. Guidelines governing the care and treatment of Alzheimer's patients are long overdue.
2. Local VA medical facilities should provide Alzheimer's disease screening, counseling, and treatment programs for veterans, their families, and care givers.
3. Recognizing that Alzheimer's disease can strike persons at a younger age, the eligibility requirements for veterans diagnosed with Alzheimer's disease should be lowered to age 50.
4. Model and/or innovative programs, e.g. adult day health care, should take into account the needs of a growing number of veterans with Alzheimer's disease and related disorders.
5. Support should be expanded for the VA's network of Geriatric Research, Education, and Clinical Centers (GRECC) program. Priority emphasis should be placed on activities involving Alzheimer's disease and related disorders.

VII. MEETING TRAINING NEEDS

Currently, very little training from either a research or a clinical perspective focuses exclusively on Alzheimer's disease.

Research

Despite increased awareness of the extent and burden of dementia in the elderly and despite very promising progress in research in recent years, considerable growth is needed in programs designed to train investigators and academic leaders in this field. A serious shortage of persons trained and committed to research and teaching in all aspects of dementia is well documented, and there are too few settings in the nation with sufficiently qualified faculty to train the needed investigators.

Recommendations

1. Provide support for career development for faculty/investigators capable of proceeding more independently in education and research relevant to Alzheimer's disease.
2. Increase the number of National Research Services Awards in the field of neuroscience, in particular those focused on Alzheimer's disease.

Clinical training

A growing understanding of improved treatment, care, and management of Alzheimer's disease requires a re-evaluation of clinical training needs and opportunities.

The specific areas requiring attention are:

Development of a training curriculum specifically targeted to treating persons with Alzheimer's disease and to providing consultation to other service providers working with Alzheimer's disease patients.

Attention to Alzheimer's disease in the basic training of clinical care providers potentially involved in the treatment of these patients (e.g., physicians, psychologists, nurses, social workers, etc.)

Continuing education for those clinicians already in the field.

Training focused on special population needs, such as the poor and minorities with Alzheimer's disease.

VIII. PROMOTING EDUCATION AND AWARENESS

There exists a fundamental need for education and understanding at all levels—from the families and physicians to government officials, life insurance companies, and administrators of pension benefit funds. Only through greater awareness can we hope to change public attitudes toward Alzheimer's and other diseases of the mind.

Recommendations

1. The federal government should continue to designate the month of November as National Alzheimer's Disease Awareness Month.
2. The Alzheimer's Disease and Related Disorders Association (ADRDA) will sponsor educational forums and disseminate information for both lay and professional people regarding the disease.
3. Throughout the year, ADRDA will continue to advise government agencies of the needs of those afflicted with the disease, as well as support research aimed at finding the cause and cure for Alzheimer's disease.
4. The ADRDA will continue to work with other national organizations where there is a shared concern for Alzheimer's victims and their families.

Mr. WYDEN. Thank you very much for an excellent statement. We very much appreciate your being with us.

Mr. Plum, we look forward to your remarks.

STATEMENT OF KENNETH R. PLUM, MEMBER, VIRGINIA HOUSE OF DELEGATES, REPRESENTING THE NATIONAL CONFERENCE OF STATE LEGISLATURES

Mr. PLUM. Thank you.

I am Ken Plum. I am a member of the Virginia House of Delegates representing today the National Conference of State Legislatures. I commend the committee on the important work that you are doing on this most critical issue.

The National Conference of State Legislatures, as you know, represents the Nation's 7,461 State legislators and their staff.

Concerning Alzheimer's disease, the Health and Human Resources Committee of the State-Federal assembly recently adopted a policy which urges:

* * * the National Institute on Aging to examine the feasibility of reassessing its priorities in the allocation of research grants to reflect the need for adequate research on this problem of ever increasing dimensions.

Already you have heard testimony and are knowledgeable of the crippling and fatal effects Alzheimer's has on its victims. You are aware of its cost to our health care systems and its toll both physically and emotionally to victims and their families. Finally, you realize the very little we know about the disease since major research on it has just started.

Due to the potentially enormous cost associated with Alzheimer's, there seems to be a reluctance at the national level and in the private sector to deal with all aspects associated with it. However, there is a need as our Health and Human Resources Committee pointed out to reassess Federal research and support priorities to insure that we adequately respond to what some are terming "the disease of the century."

In the interim, the States are not standing by idly. This year at least 11 States will consider bills to aid Alzheimer's victims and their families or to fund research projects related to the disease. I hope that these actions, that I will describe briefly, will prompt additional Federal incentives for States to do more.

California was the first State to pass extensive legislation on Alzheimer's. During the 1984 legislative session, the State legislature enacted bills that would: one, provide \$4 million for Alzheimer's disease diagnostic and treatment centers; two, allocate \$1 million for adult day health care; three, allocate \$450,000 for day care centers, a task force, and various pilot projects related to the disease.

The task force mentioned above is to study the needs of Alzheimer's patients and to sponsor a statewide conference to identify program needs and legislative goals. Finally, bills were passed to establish a service program for brain-impaired adults, and to allow skilled nursing facilities to provide specialized services for patients with progressively disabling diseases such as Alzheimer's.

The California State Legislature is also urging the Reagan administration and the Congress to amend the Social Security Act to allow persons with chronic brain disorders to be reimbursed for the cost of their care under Medicare.

This year, the Illinois Legislature is considering a legislative package that would provide for grants to promote research, diagnosis, and treatment of Alzheimer's; the establishment of an Alzheimer's registry to collect and analyze information about the extent and severity of the disease in Illinois; funding for pilot projects to determine the feasibility of providing Medicaid coverage for Alzheimer's patients.

Several years ago as a result of legislation, I introduced, Virginia established a Research Award Fund that now amounts to annual appropriations of \$40,000. This money is used to stimulate research activities, encourage private donations, and raise public awareness. This year, the Virginia General Assembly approved my resolution to establish an Alzheimer's Disease and Related Disorders Study Commission. We will be looking at the need for an Alzheimer's registry, the need for regional dementia centers, and the need for additional support for victims and families. I postponed introduction of a bill I had drafted to require optional coverage for Alzheimer's disease as part of health insurance plans, pending the conclusion of our study.

Other States who are active include: Connecticut, which is debating proposals aimed at funding Alzheimer's disease support groups and training day care personnel; Washington, which is considering legislation to relieve those who care for Alzheimer's and other patients; New Jersey, which provides \$115,000 to fund a day care program at a New Jersey hospital for Alzheimer's patients; and Nebraska, which is considering a bill that would require Alzheimer's disease benefits be included in private health insurance policies. Many other States are also considering legislation on Alzheimer's and I will provide their actions to the committee as part of my followup report.

Briefly, I would like to outline some areas for Federal action which will provide the States with incentives to continue their efforts related to Alzheimer's. While it is difficult to ask for additional Federal financial support in light of the Federal deficit, we need to be equally concerned about the bankrupting effect—both in dollars and morale—that Alzheimer's has on its victims and their families. I would like to suggest there may be ways that both the Federal Government and State governments might be mutually

supportive in designing methods to meet each level of governments' goal to do what is necessary to assist victims and their families.

First, a comprehensive look at both the Medicare and Medicaid programs should be made to determine if there are ways to provide additional support for victims, especially their long-term-care needs. A significant percentage of those persons requiring long-term nursing home care are Alzheimer's patients.

Second, a catalog of State and private programs should be developed at the Federal level to document programs, to assist in coordinating programs, and to provide a foundation of technical assistance to the States as they establish programs. Particular attention should be given to research funding available to supplement or match States' efforts in Alzheimer's research. The costs of research will be minimal compared to the costs of care of 2.5 million current victims. We need to get ahead of this dread disease in finding its causes and developing cures before it bankrupts us as a society.

Finally, incentives should be developed at both the State and Federal level to encourage private health insurance or other private health funding for the care of Alzheimer's patients in either their homes or in nursing care facilities before victims are forced into poverty. The financial obligation for support of Alzheimer's victims is substantial and can be borne only by the Government and the private sector working together.

In conclusion, I would like to offer the services of the National Conference of State Legislatures to the committee to develop proposals which address the issues raised here today.

Thank you for providing me this opportunity; I am available for your questions.

Mr. WYDEN. Thank you for a fine statement.

Dr. Reifler.

STATEMENT OF BURTON REIFLER, M.D. DIRECTOR, ALZHEIMER'S CLINICAL RESEARCH CENTER, UNIVERSITY OF WASHINGTON, SEATTLE, WA

Dr. REIFLER. Mr. Chairman, members of the committee, I am honored to be here and in my comments on Alzheimer's disease I would like to review five basic points. I would like to review some of the advances we have made in research and then discuss elements of the diagnosis, cause treatment, and implications for the future.

The general theme of my comments will be that despite encouraging progress, we really have just begun. The major advance in the 1950's was that for the first time we began to count numbers of patients admitted to hospitals with complaint of memory loss. In the 1960's, we discovered that this process was not due to hardening of the arteries and that the diagnosis was the same for people under 60 as for people over 60. As a result of these developments, we have been able to discard the concept of senility as a normal consequence of aging and now realize that memory loss associated with old age is not normal but it is a disease.

In the 1970's, we discovered that patients with Alzheimer's disease had a reduction in a specific chemical in the brain, namely

acetylcholine. This represented a breakthrough and for the first time gave us rational ways to test new medications.

Also in the 1970's, we began to pay proper attention to diagnosis and to treatment. The 1980's have seen the development of centers funded by both NIMH and NIA, the development of the Alzheimer's Disease & Related Disorders Association, and a great expansion in the clinical and research base.

As a result of these developments, we now have scientific hypotheses we can test, and the scientific community is ready to mount a major effort against Alzheimer's disease.

Let me make some comments about the diagnosis.

Adequate diagnosis is best done by proceeding from multiple points of view. Medical, psychiatric, social, and environmental.

The clinic I started in 1978 for Alzheimer's disease was the first on the west coast, and it was met with considerable skepticism. People predicted there would be no demand and we would need heavy subsidy just to keep going. We have had a waiting list since we opened, we have now seen 1500 patients, we are self-supporting, and there have been many clinics replicated after ours.

The diagnosis of Alzheimer's disease is based on the fundamentals of medical practice: A history of the patient's illness—in this case the history is best obtained from the patient's families, because the patient simply cannot give you an adequate history—the physical examination to rule out other causes of dementia and also to look for coexisting illnesses, and a mental status examination.

The CT scan is helpful in ruling out other causes of dementia, not in ruling in Alzheimer's disease, and some family members have the misimpression with the CT scan you can see individual brain cells. Some of the new high technology procedures, such as PET and NMI, are research procedures and do not have a day-to-day role in the diagnosis at the moment.

I think an interesting barrier to diagnosis was something that I might not have predicted early on, and that was that it was difficult to diagnose Alzheimer's because Medicare wouldn't reimburse you if you made that diagnosis. I remember some patients I saw who would receive claim determinations back saying that memory loss associated with normal ageing is not an illness and treatment designed to help people cope with that problem is not covered by Medicare.

Some patients become so disillusioned that they were demoralized and would not seek further treatment. Fortunately this is now being corrected but I am not convinced that we have corrected it completely. A few weeks ago I received a letter on a Medicare claim determination that indicated I had not been providing active treatment to a patient because I hadn't started a new medication or changed the dose. I wonder if I would have gotten the same interpretation if it had been a diabetic on insulin and I had left the dose of insulin the same?

Let me make a few comments about the causes. I have spelled out the theories of cause in my written testimony, let me just mention our best theory which is the deficiency of acetylcholine, a consistent finding in the brain of Alzheimer's patients. Unfortunately, this finding has not yet been translated into effective treatment.

This leads me into treatment, and my statement would be that although Alzheimer's disease is incurable, we shouldn't regard it as untreatable. There are many other diseases that are incurable for which we have safe, effective, proven forms of treatment. Among these are diabetes, many forms of cancer, and most forms of heart disease. The same principle, that although Alzheimer's is not curable, that it is treatable, should apply. For example, there are many behavioral complications for which we have excellent treatment, including depression and paranoia. About half the patients we see with Alzheimer's disease have some coexisting illness and in about half of those when we treat that coexisting illness, we see clear improvement. This concept is known as excess disability.

I know of no other group of patients who are at such high risk for undetected problems because they cannot articulate their problems to the physician.

We also have community programs that are useful forms of treatment, particularly adult day centers where the patient can receive structured daily activity and the family member has the opportunity for respite.

Everyone wants to see a cure, and it becomes very easy to exaggerate. For example, in the very fine article in this morning's paper in U.S.A. Today, there was an implication that drug treatment can delay deterioration for up to 3 years. There really is no convincing evidence for this. I think that some patients do have plateaus. At this point, we don't know if it is due to the medication or if it would have happened anyway.

This immediately suggests two lines of needed research. One to test the medications themselves, and another to study the natural history of the disease. Unless we know how many patients have plateaus we cannot hope to adequately test new treatments.

Let me now conclude with a few comments about implications for the future. I would like to tell you a story about a family who came to see me. Several years ago, a woman brought her mother in to see me; I made the diagnosis of Alzheimer's disease, the woman was disappointed that we had no cure for her mother, but she was relieved to know the problem had a name.

When I first told her the diagnosis, she thought I had said old timer's disease, a not uncommon occurrence 5 or 6 years ago.

I saw the daughter again a few months ago, this time brought in by her husband, this time she was the one we diagnosed as having Alzheimer's disease.

This was a difficult experience for me, and frankly it made me a little bit angry. I had great compassion for the family. They have my admiration and respect. But I was angry that even though I could now tell her husband more about the disease—he had heard the name, I could tell him about theories of cause, I could tell him about community programs—I still have nothing to reverse it, to stop it, or even slow it down.

Now I pray that I never have occasion to see their children as my patients. If I do, I certainly want to have a lot more to offer them than I had to offer their mother or their grandmother.

Other people have eloquently spoken to the disparity between what we spend on long-term care versus research. We currently

spend about \$25 to \$30 billion on long-term care, \$43 million for research education.

The amount we spend on long-term care, I think even Senator Dirksen would have said this amounts to real money.

To take it to the level of an individual patient, we currently spend about \$10,000 a year to care for a single patient with Alzheimer's disease, we spent less than \$15 per patient per year on research.

I urge passage of this important bill this year and I urge a very substantial increase in funding for next year. I think you and I have the opportunity to leave our children and our grandchildren a great legacy, both human and economic. The legacy is that we saw what needed to be done, and we moved forward to accomplish it.

Thank you.

[The prepared statement of Dr. Reifler follows:]

PREPARED STATEMENT OF BURTON V. REIFLER, MD, MPH, DIRECTOR, ALZHEIMER'S CLINICAL RESEARCH CENTER, UNIVERSITY OF WASHINGTON, SEATTLE, WA

Alzheimer's disease is the leading cause of irreversible memory loss in the elderly, directly affecting as many as three million Americans and their families. In my testimony today I would like to cover five areas: (1) a review of the advances that have occurred in research on Alzheimer's disease, (2) the diagnostic evaluation, (3) theories of cause, (4) principles of therapy, and (5) implications for the future.

I. REVIEW OF THE ADVANCES IN RESEARCH ON ALZHEIMER'S DISEASE

The term Alzheimer's disease was unfamiliar to most people until the last few years. Alzheimer's original description, shortly after the turn of the century, was of a few patients under age 60 who had what he termed "premature senility". The medical community regarded the same symptoms of diffuse intellectual impairment as normal aging in people over 65. This is where things stood until half a century later.

In the 1950's researchers in Great Britain began to provide the most basic descriptions of mental illness in the elderly, simply classifying different types of problems by counting the number of people with each who were admitted to hospitals. Dementia in the elderly was now defined as a disease, thus challenging the concept of senile dementia as a normal consequence of aging. Unfortunately, the myth that advancing age inevitably brings mental confusion still lingers, although the evidence is now overwhelming that the vast majority of older people are mentally alert.

Two major development occurred in the 1960's. First, pathologic studies showed that changes in the brain were the same for affected individuals over the age of 60 as for those under 60. This meant the age distinction between Alzheimer's and so-called senile dementia was an artificial one and they were essentially the same disease. The second development was the finding that Alzheimer's was not due to poor blood supply and therefore the term arterio sclerosis was generally inaccurate when applied to this group.

The two major development of the 1970's were (1) identification of specific chemical abnormalities, and (2) careful attention to diagnosis and therapy. Several laboratories recorded reduced levels of acetylcholine in the brains of Alzheimer's patients, thus providing a rational approach to the search for drug therapy.

Alzheimer's clinics were virtually unheard of until the late 1970's. Our clinic at the University of Washington, Geriatric and Family Services, was the first clinic on the West coast to specialize in Alzheimer's disease and has now provided over 1500 evaluations and has been replicated by at least 8 other centers. Alzheimer's clinics now exist in many major cities.

The 1980's have seen an enormous increase in research and clinical activities on Alzheimer's disease. Federal support for research has increased from roughly 8 million dollars in the late 1970's to over 40 million dollars in 1985 (a substantial percentage increase, but a total dollar figure that is still woefully below what is needed). We have also seen the development of a national organization on Alzheimer's disease (the Alzheimer's Disease and Related Disorders Association), and the development of Alzheimer's centers funded by NIMH and NIA.

II. DIAGNOSTIC EVALUATION

I will describe our clinic, Geriatric and Family Services, to illustrate some of the elements of the diagnostic evaluation. The clinic is a multi-specialty, outpatient, family oriented program and the diagnostic evaluation consists of a psychiatric examination, physical examination, psychological testing, and a social and environmental assessment. After the evaluation is complete, we have a staff conference to review the findings and develop our recommendations, which cover the following areas: (1) stop or start medication, (2) additional medical treatment, (3) environmental modifications, (4) counseling for the patient and/or the family, (5) additional help at home, (6) referral to specific community programs, (7) respite for the caregiver, (8) legal and financial considerations, (9) referral to the local chapter of the Alzheimer's Disease and Related Disorders Association, and (1) participation in specific research projects.

One rough classification for making the diagnosis of Alzheimer's is to think of three stages, which in order of severity are: (1) forgetful, (2) confusional, and (3) demented. Taking these in reverse order, patients in the demented stage have difficulty with virtually every aspect of daily life, are unable to dress and feed themselves, and cannot carry on any meaningful conversation. Diagnosis at this stage is based on excluding other causes of dementia by taking a history from the family and performing a complete physical examination with appropriate laboratory studies.

In the confusional stage, the patient may appear normal at first glance, but on mental status examination, will show conspicuous errors in many mental functions, such as memory, orientation, calculation, and judgement. History provided by the family will reveal clear deficiencies in many aspects of daily living, but since the individual may retain rudimentary social skills, these problems may not be apparent to casual observers, who may mistakenly believe the family is exaggerating about the patient's problems. The diagnosis at this stage is based on obtaining a history of gradual progressive loss of mental ability and ruling out other potential causes.

At the forgetful stage, the diagnosis can be very difficult and by far the most important element is the history provided by the family, particularly the wealth of anecdotes that indicate a clear decline from what was normal for that person. For example, the individual may repeatedly get lost on trips, may ask the same question over and over, and may show dramatic difficulty in managing personal finance. For any of these to be useful as clues to mild Alzheimer's disease, they must occur repeatedly and be clearly abnormal for that person. My colleague at the University of Washington, Eric Larson, M.D., has developed the following diagnostic strategy in Alzheimer's disease. In order of importance, the elements are: (1)(a) the history of the patient's illness (including history obtained from the family, (b) complete physical examination, and (c) mental status examination; (2) screening laboratory tests; and (3) other tests (including CT Scan) on a selected, not routine, basis.

We put the greatest emphasis not on high technology diagnostic procedures, but on the traditional elements of medical practice—the history and physical examination. We do not believe CT Scans are required in every patient, and have found that in individuals with a gradual deterioration of at least three years, dementia that is moderate to severe, and nothing in the history or the physical examination to suggest the need for the test, the CT Scan has been of no additional help. Many families have the misimpression that the CT Scan can firmly establish the diagnosis and that individual brain cells can be seen on the Scan. In fact, it does not rule in Alzheimers disease, but rules out other conditions, and only shows regions of the brain, not individual cells. Newer radiologic procedures such as PET and MRI are of great research value, but have no useful role in the routine diagnostic assessment.

We are struck by one specific finding that has emerged from our diagnostic evaluations; a great many patients with Alzheimer's disease have treatable illnesses that are needlessly adding to their difficulties. The term for this is excess disability. Roughly half of the Alzheimer's patients we evaluate have some illness causing excess disability and with appropriate treatment, about half of this group shows clear-cut improvement in mental functions, physical health, or activities of daily living. Examples of these coexisting conditions include depression, overmedication, Parkinson's disease, thyroid abnormalities, and many other medical and psychiatric conditions. Because of the obvious difficulties patients with Alzheimer's disease have in articulating their complaints, I know of no other group of patients at such high risk for undetected medical or psychiatric illness.

In some centers, a barrier to accurate diagnosis came from an unexpected source; Medicare intermediaries refused to recognize the diagnosis. In 1982, one of my patients with Alzheimers disease received the following claim determination:

"Memory loss associated with the normal aging process is not considered an illness." The patient's daughter sent me a letter in which she stated, "My mother was shocked and dismayed to read this determination. She has lost hope of improvement." My colleagues and I are pleased with the recommendations from the Secretary's Task Force on Alzheimer's disease that promised to correct this problem, but another recent experience indicates to me the problem is not yet solved. In a letter I received from a federal Medicare intermediary dated April 18, 1985, payment was denied on the basis that the patient was not receiving "active treatment". The letter stated, "In order to be a covered service by Medicare, the services must be providing 'active treatment,' i.e., new medications or medication changes." This interpretation creates a dilemma since it is often impossible to know if medication changes are necessary without first seeing the patient. While it is crucial to control health care costs, it is unwise to do so by creating conditions for payment that run contrary to sound medical practice.

III. THEORIES OF CAUSE

Most theories regarding the cause of Alzheimer's disease fall into five categories, which are not mutually exclusive:

A. Acetylcholine Deficiency.—This is the most promising development so far. Numerous investigators have found that the brains of Alzheimer's patients have a significant decrease in acetylcholine, one of the major neurotransmitters that carries messages from one brain cell to the next. Attempts to treat Alzheimer's by enhancing the action of this missing chemical have been generally unsuccessful to date, but hold enormous potential for the future.

B. Genetic.—Genetic factors play a role as a risk factor, but the details of this association are unclear. Many families are hit particularly hard and in some instances children of affected parents appear to have a 50/50 chance for developing the disease.

C. Slow virus.—Some viruses remain in the body for many years before signs of illness appear. There are two rare causes of dementia that appear to be viral, and these are Kuru and Jakob-Creutzfeld disease, but attempts to transmit Alzheimer's disease to laboratory animals have been unsuccessful, and there is no evidence of human to human transmission.

D. Autoimmune.—This refers to the body's immune system making antibodies to brain cells. This theory remains unproven.

E. Aluminum.—There have been reports of increased aluminum levels in the brains of Alzheimer's patients, but this has not been consistently replicated. The current belief is that if aluminum plays any role it is a secondary one and that aluminum build-up occurs only after something else has damaged the brain cells.

IV. PRINCIPLES OF THERAPY

It is no longer enough just to make an accurate diagnosis. We now have the knowledge, experience, and resources to make specific recommendations and establish a treatment plan for each patient.

It is correct to say that Alzheimer's disease is incurable, but incurable does not mean untreatable. There are many other incurable diseases, including diabetes, emphysema, most forms of heart disease, and many types of cancer, but there are effective, proven treatments for all of these. The same principles apply to Alzheimer's disease as there are effective treatment approaches at every stage of the disease. Among the essentials of any treatment program are the following:

A. Preserve existing abilities and function.—Patients with Alzheimer's disease should be encouraged to do everything they can for themselves, even if it isn't quite as good as before. There appears to be a "use it or lose it" phenomenon.

B. Treatment coexisting illnesses.—As I noted earlier, about half of Alzheimer's patients have some other illness and treatment of this coexisting illness often leads to marked improvement. An example I sometimes use to illustrate the concept of excess disability is to ask people to imagine a man who is wearing a cast for a broken leg. Now imagine a ball and chain attached to that leg. The ball and chain represents excess disability, which can easily be removed. The person still has his broken leg, but now he can get around. For patients with Alzheimer's disease, overmedication, depression, Parkinson's disease, or thyroid difficulties can act like a ball and chain.

C. Use community programs.—Of particular benefit are adult day centers where patients with Alzheimer's can participate in a structured daily activity program, and as a fringe benefit, the caregiver has the opportunity for respite (or in many cases the chance to earn a living).

D. Treat behavioral complications.—Two prime examples of treatable behavioral complications are depression and paranoia. There are effective treatment strategies both with and without medication, which can help substantially.

E. Educate caregivers.—Caregivers need advice and guidance on every aspect of the disease. For example, we can advise the family that although Alzheimer's is generally steadily progressive, a significant minority of patients (perhaps one third of those) will have periods of stabilization lasting up to several years.

Please note that effective treatment can involve any number of medical disciplines. Psychiatrists, internists, family physicians, and neurologists all have much to offer if they are interested and informed. Likewise, many community agencies and social and health professionals have a role in managing the problems of Alzheimer's disease. Needless arguments about who can best help do not serve our patients or your constituents.

V. IMPLICATIONS FOR THE FUTURE

Recently I saw a woman I first met five years earlier when she brought her mother in for an evaluation. I made the diagnosis of Alzheimer's disease and while the daughter was disappointed that we had no cure, she was relieved to know the problem had a name and that she was doing all she could.

I saw the daughter again a few months ago. This time her husband brought her in, and this time she was the one I diagnosed as having Alzheimer's. I was able to tell her husband many things that were unknown when I first met his wife. We talked about research developments on the chemical deficiency theory of Alzheimer's, I advised him about the availability of adult day centers, told him about genetic aspects of the disease, (in his family's case, these were not encouraging statements), and mentioned our newly funded Alzheimer's disease clinical research center, but I could not tell him that we now had an affective treatment to halt the disease or even slow it down.

I hope his children never become my patients, but if they do, I want to have a good deal more to offer than I do now. And for my colleagues and I to have improved forms of treatment, it will take much more than our current expenditures of 40 million dollars annually. The alternative to increased funding for research is staring us in the face. By 2020, the over 60 population will have doubled, and the nation's resources will be strained far greater than they are now to pay the billions of dollars in nursing home costs we will face. As the man said, "You can pay me now or pay me later."

We have made encouraging progress. People have heard of Alzheimer's, it is now recognized as a disease rather than as normal aging, there are diagnosis and treatment centers in many cities, we have affective treatment for many of the symptoms, there is active research at many universities, there is a national organization of support groups, and through efforts such as those of this Committee, Congress is beginning to listen. But we have really just started. We are like explorers who reach the crest of a hill, hoping the destination is in sight, only to find a mountain range on the other side. The challenges we share are to mobilize the resources, develop the plan, and carry out the effort to cross the mountains, and if we all work as hard as we can at the things we do best, we can reach this goal.

Mr. WYDEN. Thank you. Ms. Mace.

STATEMENT OF NANCY L. MACE, M.A., BOARD MEMBER OF ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION [ADRDA], AND MEMBER, MARYLAND TASK FORCE FOR ALZHEIMER'S DISEASE

Ms. MACE. Thank you very much, Mr. Chairman, members of the panel. I am happy to be here today to speak with you.

I am a member of the board of directors for the Alzheimer's Disease Association, and am also a member of the Maryland Task Force for Alzheimer's Disease.

On behalf of the Alzheimer's Disease Association, I would like to tell you that that organization does strongly support this bill. I am also working under a contract with the Office of Technology Assessment on a study of the long-term care needs of patients with

disorders causing dementia. My remarks today should not be interpreted as a statement of the OTA's position.

As you know, there have been a number of studies looking at the impact of this dreadful disease on families, and certainly we have heard many families speak of this. These families that you hear in testimony are not what jargon calls the outlayers, they represent the experience of the vast majority of families.

A study that Elaine Brody recently completed in Philadelphia, found that the daughters of impaired elderly women were leaving their jobs in order to provide care. I think this speaks not only to the family's suffering but to the impact on the labor market.

A few days ago, I received a call from a woman who did not know me but had gotten up the courage to call me because of who I am. She said to me that her back was to the wall, she was desperate, she could think of nothing to do but to shoot herself and her husband. She was 76 and she had been caring for an Alzheimer's patient for 12 years.

As I talked with her, I realized that the majority of the problems that had led her to this immediate crisis and feeling she could no longer go on, were problems of what Dr. Reifler has called excess disability, and had I been able to refer her to him or to the excellent teams in several other cities, the problem, not the disease, but the problems that were overwhelming this woman could have been corrected in a couple of days.

It was extremely difficult for me to tell her there was nothing I could do because she didn't live in San Diego or Baltimore or near Dr. Reifler.

You hear from families who are here and you hear—we heard from many families at the recent NIH Conference. I want to point out to you that those families are the ones that are able to get themselves together and come to Washington. There are a lot of families out there who are not surviving well enough to do that kind of thing, and I think we should speak for them, also.

We know now that one of the key ways to assist caregivers is to give some respite for them, and I think that the bill that we are discussing today speaks to that critical need.

Respite comes in many kinds, it comes as help in the home, it comes as overnight or short-term care in the home, it includes day care, it includes short-term residential board and care while a family member goes into the hospital, for example, and for some patients who don't have families or are too ill, residential or nursing care is needed.

We have talked a lot about the need for respite services to ease the burden. I want to followup what Dr. Reifler has said and emphasize that we do know now that we can also alleviate much of the patient's suffering, while we cannot alter the course of the disease.

We can with our present level of knowledge provide therapeutic care for the patient and the respite resources that I am speaking of are ways for us also to improve patient function and improve patient quality of life.

I have had the good fortune to be traveling around the United States looking for the extremely rare and special programs that

are doing this, and let me describe for you what I have been calling the best of places and the worst of places.

I visited a hospital in which there were 50 patients either drawn up in their beds, or slumped and dozing in chairs. They were unaware apparently of me, they were certainly unaware of the two patients in the room who were screaming monotonously and probably would continue to scream for many days.

I went from there to Wesley Hall in Michigan where I saw a ward with approximately equally impaired patients. The floor was carpeted because continence was no longer a problem. The ward was unlocked because these patients no longer wandered away.

They sat and chatted with me, they showed me their rooms and they served me the muffins that this group of women had baked.

Both of these facilities are seeking to give good care. However, only one of them has had access to the still quite rare skills that we have in providing quality care for these patients, and I questioned both facilities at great length about their cost and learned that the smaller units at Wesley Hall, which was a very fine unit, cost \$38 a day per patient less than the other facility.

In a published description of the Wesley Hall facility, they state that there is a dramatic reduction in continence, the patients are now sleeping through the night, they have resumed old household tasks, they are making friends. In a survey that I did of the day care centers throughout the United States, I found equally astonishing findings.

I believe that our charge for the coming decade through bills such as this one is to determine just how far we can go in maximizing patient functions and maximizing the quality of life in removing excess disability.

Dr. Reifler pointed out we do things for other people who have chronic diseases, we teach diabetics how to manage their diets, to minimize this impact of their illness. We make the environment accessible to the paraplegic, when the cancer patient becomes depressed we treat his depression. We can do these things for the patient with dementia also and we must begin to do so.

For example, there are studies that show that when a person with a dementia is admitted to the emergency room, the dementia is not picked up, it is not noticed. Often patients who are in hospitals and in acute care, the dementia is not noticed.

How can you discharge a patient with a treatment plan if you don't know that he cannot think right.

I think we have just begun in a very, very small way to ask what the rehabilitative therapies can do for these patients. We have hardly begun to ask at all what the potential is for high tech in helping our patients. I can tell you that better technology for managing incontinence and for controlling patient wandering would be a very, very valuable gift for families.

We have models for all of these programs that I have seen, but they are so rare that I can almost count them on my fingers.

We need desperately to encourage the dissemination of that knowledge which now exists and we need to continue that. We need to give each other feedback rapidly on what we have tried that worked.

At the present time, it seems to me that our service delivery produces about as many tangles in service delivery as it does in the brain of Alzheimer's patients. We seem to be living in a world of fragmented un-networks in caring for these people.

It is really hard for us to know that we do know how to do things much better.

To quote Martin Luther King, "I have a dream." The program that I described to you at Wesley Hall is a good model program. It is about to terminate. The staff who set it up will be withdrawing. I wish that instead of that happening, we could set up 5 or 10 such model centers that provide day care, residential care, short-term care to patients, that experimented with the very best ways to keep them as functional as possible, and that were there for the purpose of bringing other care-giving professionals in to teach them those skills.

It isn't easy to identify and teach those skills. I believe that if we had a group of such centers as patient care teaching facilities throughout the country, we could really begin to get something going.

The legislation we are discussing today I think sets the stage for my dream.

Thank you.

[The prepared statement of Ms. Mace follows:]

PREPARED STATEMENT OF NANCY MACE, M.A., BOARD MEMBER, ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION [ADRDA]

Thank you for the opportunity to address you on the needs of victims of dementing illnesses and their caregivers.

I am a member of the board of directors of ADRDA and a member of the Maryland Task Force on Alzheimers disease. I am also working under a contract with the OTA on a study of the long term care needs of patients with disorders causing dementia. My remarks today should not be interpreted as a statement of OTA's position.

Clearly we are dealing with a problem of epidemic proportions and clearly the caregiving families are as much victims of this epidemic as are the patients.

As research on the impact of dementia on caregivers grows, a more telling picture emerges. A study from Duke University reports that caregivers may turn to tranquilizers or alcohol in their struggle to cope with the endless pressures of care. Elaine Brody's work at the Philadelphia Geriatric Center found that many women are leaving jobs to care for their frail parents—data that has meaning for caregivers, their children and for the national economy.

Studies have shown that often caregivers are chronically depressed, a finding which has implications for their work productivity as well as the reflection of personal tragedy.

The tasks of caring go on for many years and this adds to their toll. A show of hands at the recent NIH conference for family members revealed that many caregivers have shouldered the enormous burdens of care not just for a few months or years but for ten years or more.

The Duke study found that caring does not end when the patient enters a nursing home. Families continue to remain very involved with their loved ones and continue to experience strain in so doing.

Recently I received a call from a woman I do not know. She knew of me however, and asked if she could talk to me for a few minutes. She said, "my back is to the wall. I don't know what to do except to shoot myself and my husband." This 76 year old woman had been caring for her husband for 12 years. She was subsisting on about three hours a night of sleep: feeding, dressing, bathing and changing diapers for a man who weighs half again what she weighs. Recently he had begun hitting her as she cared for him. Finally she had gone in search of a nursing home, and found out that for her husband to qualify for financial assistance she would have to impoverish herself. She said to me, "if only I could get a little rest, then I could

think what to do, and keep on caring for him." Tragically I knew of resources that could help her, but there were none in her community.

Demographics indicate that as the population ages, caregivers will be older like this woman, and with their own chronic illnesses. As there are more single person heads of household and fewer children, there will be even fewer family members available to share the tasks of caring.

A man I know is getting up early to dress and feed an Alzheimer victim, leaving her in precarious situations while he goes to work, and doing his job with half his mind on whether the patient has turned on the stove and set a fire, or wandered into the street. He too manages on only a few hours sleep and worries about what will happen when his mother can no longer stay alone.

There are children in an unknown number of these homes. We really don't know much about the impact on children or adolescents of having a person at home who doesn't recognize them or who acts crazy, but as one caregiver said, "it sure didn't help them any." Young adults are postponing marriage or not having children because of their fears about the as yet unproven issues of genetics.

At the recent NIH conference caregivers told moving stories of their struggles. But as one of them pointed out, those who were there were the survivors. How many are not surviving, giving in to alcohol or drugs, succumbing to stress related illnesses or living in the dim light of depression.

We have learned that caregivers need information about the illness, about caring, about resources, and that caregivers need the on-going support of the medical profession to keep the patient as healthy as possible and to manage his symptoms. We know that voluntary support groups help the caregiver in many ways. Caregivers need friends, family, clergy and sometimes professionals to help them manage their own grief, anger, frustration and despair. Skill in managing symptoms helps caregivers respond appropriately to the strange and sometimes frightening behavioral disturbances these disorders can cause.

We also know now that one of the key ways to assist caregivers is to provide respite from the 36 hour day of caring. Bills such as yours speak to this critical need.

Most dementia victims live at home. Respite care at home may include trained people who can take the patient for walks, play tennis with him, or just sit with him while the family member gets out.

Home respite may be someone who can stay overnight for several days in the home, while the family caregiver takes a much needed vacation or cares for her own health needs. Other settings accept short term residential patients for a few days or weeks.

Respite includes day care which relieves the caregiving family for a few hours or enables an employed caregiver to continue to keep a patient at home.

Some patients cannot live at home or have no family member to care for them. For such people, residential board and care offers the family a necessary alternative.

For the very ill a residential setting may be needed that provides medical and nursing care as well as structure, safety, comfort and peace, with carefully supervised medication, no restraints, good diet and good skin care.

Hospice-like programs provide compassionate care for family and patient in the last days of the illness.

So far we have focused on the urgent need for respite services to ease the burden on caregivers. However, I am becoming increasingly convinced that same services which offer families respite can also be therapeutic for the patient.

We can, with our present level of knowledge, provide therapeutic care for the patient. In thinking of the need for services, including respite care, this must be considered. We are not limited to warehousing hopeless people so that the families can get a breather.

To illustrate this point, I shall describe for you two facilities I recently visited. To paraphrase Dickens, they were the best of homes and the worst of homes.

In the latter setting the patients lay slumped in geri-chairs in a large, grey, poorly lit room. They were dozing, oblivious of the television set in their midst, and apparently unaware either of my presence or of the two patients who screamed monotonously and endlessly. There were seven toilets for 50 patients. When I expressed surprise at this I was told that most of the patients were "too far gone" to use the toilet. Indeed, most of them were nude from the waist down for ease of mopping.

In Michigan at Wesley Hall an approximately equally impaired group of patients proudly showed me their homey rooms and served me muffins they had baked. The residents were nicely dressed and the floors were carpeted because continence was

well-managed. The doors were unlocked because the patients no longer wandered away.

Both facilities sought to give good care; only one had applied all that is now known about the special kind of care these patients need. The daily cost of care, by the programs' own reports was \$38 day higher in the first facility.

In the best of settings day care offers both respite for caregivers and a place where the patient can socialize, a place where he senses that he is both accepted and is making a contribution, a place for the patient to make friends. In home care becomes more than just a sitter service: it may be an opportunity to initiate therapeutic interventions that the exhausted caregiver cannot provide. Residential care becomes a place where the patient can live in a setting that makes him feel at home, allows him to feel useful and secure, a place where setting the table is something she can still do; a place that does not demand intellectual skills but supports social skills.

Dorothy Coons, writing about Wesley hall, says, "there has been a decided reduction in incontinence . . . by the fifth month, most of the persons were sleeping through the night . . . patients resumed old household tasks, become friendly and warm . . . wandering has been reduced . . ."

In a survey of day care programs which I conducted at Johns Hopkins, and which was funded by the Wood Kalb foundation, I found that 84% of the centers reported that their demented clients made friends at the center; 67% reported that wandering declined; and 71% reported that agitation decreased.

Staff of special programs report that they use fewer medications—that is they are taking patients OFF behavior controlling medications and OFF sleeping medications, they use no restraints—which cost money to monitor. The patients are walking more, talking more, and seem more like their old selves.

Some settings report that some of their patients are remaining mobile until close to the terminal phase of their illness. They use fewer catheters and diapers, are less agitated and have fewer episodes of combativeness.

I believe that our charge for the coming decade is to learn more about what we can do to provide the best of care, to rehabilitate patients, to enable them to live with their illness, to improve their function, to remove excess disability, and to improve the quality of their lives.

We cannot cure the most prevalent of these diseases yet, but we can't cure many diseases. When we cannot cure a chronic disease, we seek to make the patient as functional, as independent and as comfortable as we can.

We teach people with diabetes to change their diet in order to minimize the impact of their disease, we treat the depression experienced by a cancer patient; we make the environment accessible to the paraplegic.

We must do as much for the dementia victim.

We have no grounds to take a stance of therapeutic nihilism because we do not have a cure for Alzheimer's disease or multi-infarct dementia.

I have discussed the burden that dementia places on families and described the importance of respite and supportive resources for families. I have gone further to state that we can also offer therapeutic interventions for the victims themselves.

I have identified four areas of patient care and treatment which may improve patient function and well being.

First, assessments and diagnosis. Common sense dictates that any person who is sick should be thoroughly assessed. But too often a person who carries a label of dementia is not fully evaluated or when other stresses, traumas or illnesses arise, the worsened condition is blamed on the dementia without enough attention given to the concurrent problems. Alzheimer's disease is not a new synonym for hopeless assessments do identify interventions.

Assessment identifies the individual's limitations and it also identifies his strengths and remaining skills.

Assessment is an ongoing process. As the patient changes, we must reassess his status, re-identify his areas of spared and impaired function, repeat the search for concurrent illness.

We must take steps to ensure that all patients receive a thorough assessment.

Second, treat all concurrent illnesses. Persons suffering from dementing illnesses need good on-going medical care. We know that if we keep these patients as well as possible we enable them to function at their best; we know that for these vulnerable persons, their thinking often worsens when they suffer even minor concurrent illnesses; we know that we must use as few medications as possible, as sparingly as possible, recognizing the risk that medication may further impair function.

Successful home and community care depends on the capacity of the community physicians to maximize their patients' general health. We must find ways to teach all physicians that their efforts to keep patients in good health are vital.

We must improve our ability to recognize a patients' problems in thinking when he enters the emergency room, the acute hospital, or the outpatient clinic.

Studies have revealed that dementia is not always noticed by clinicians in the emergency room and is not always diagnosed in in-patient acute settings. In addition patients care sometimes discharged before plans have been made for care that takes into consideration both their difficulty thinking and other illnesses. How can we treat the patient if we don't notice that his thinking is impaired?

Third, treat the patient's disabling symptoms. Patient depression, hallucinations, extreme suspicion, agitation, and wakefulness at night often do respond to treatment interventions.

Gene Cohen points out that there is a distinction between these forms of active treatment of the patient and the equally important tasks of providing good care and management, and these interventions often make it possible for a person to use resources which give the family some respite.

Fourth: make the patient's environment work for him. Dorothy Coons, director of the Wesley Hall project says, "each of the environmental components—the programs of activities which makes up the daily life of the individual, the staff, the physical setting, and other residents—has the potential for becoming a therapeutic or nontherapeutic agent in treatment."

A supportive environment recognizes the patient's limited ability to tolerate stress and helps the patient withdraw when demands, noise or confusion become too much. A supportive environment reacts with calm and reassurance to disturbed behaviors. It recognizes the patient's need for a social life and offers him ways to maximize his old skills.

It may be, as some have theorized, that a barren environment encourages restless, agitated, repetitive or socially unacceptable behavior.

It appears that, because these patients have limited ability to initiate, organize and plan, they need extensive input from their psychosocial environment to enable them to socialize or do meaningful tasks.

The environment allows for individual choice without too much pressure for difficult decisions; it fills in when a person falters; it simplifies tasks and at the same time provides an opportunity to do meaningful work that supports a sense of self worth. In some day care programs patients earn small sums of money for such tasks as folding newsletters, and stuffing envelopes.

How much more can the environment do for victims of a dementia? Which physical settings, and which activities support function? What can architects, human engineers, products designers and others offer to help these patients? Can walkers, hearing aides, corrective lenses and incontinence wear be made easier for confused people to use?

In addition, we have only just begun to explore the potential in rehabilitation therapy, speech therapy, physical therapy, occupational therapy and other therapies in helping patients compensate for their disability. Rehabilitation therapy for these patients is different from rehabilitation therapy for a person fully able to learn new. We need therapists with the talent to search out new ways to help memory impaired people.

High tech may also offer resources to help our patients. Certainly we don't want to replace tender loving care with robots but we have not yet begun to explore what these technologies can offer our patients. Systems which alert the caregiver that a patient is wandering or systems that automatically turn off the stove would allow caregivers to sleep restfully at night. Better technologies for the management of incontinence will be gratefully received by families.

We have models for some of these services, but they are rare, far too rare to serve the estimated 2-4 million patients and their families. They are but the vital needs with which to begin to build a network of care resources. A high quality, coordinated, accessible care network is as yet only a vision, but what we have clearly demonstrates that the investment of our limited funds into patient care research and models of service delivery is a wise and human investment.

We need policies which support innovative experimental patient care techniques and service delivery systems.

We need policies which encourage the dissemination of information. We need to spread knowledge quickly and widely and we need to systematically share what we learn, rapidly, generously and efficiently. We need to develop a large cadre of people trained in the new skills as fast as new skills are developed.

It is unlikely that we can do this with a fragmented, 19th century system of communication. Other disciplines have discovered the value of computer communications in settings where rapid change in the knowledge base occurs. A system somewhat like a computer bulletin board used by researchers and care providers would be a relatively cost effective and fast way to exchange information about techniques, deliver current information to new programs, and to broaden the base of patients from which we can learn.

We need care resources that are available, equitable, accessible, and coordinated. At present, the delivery of services for persons suffering from a dementing illness seems to be more filled with plaques and tangles than are the brains of the victims. Some families report that struggles with inadequate, poorly coordinated, expensive services causes them more anguish than does the disease itself.

Fragmented unnetworks will not help us care for these patients. There are too many patients, too many difficulties in their care, it is too costly and too overwhelming a problem to risk the kind of fragmentation and competition that has marred other programs.

At the same time that we develop innovative programs we must give thought to the difficult issues of quality assurance. I have observed programs that say that regulations designed to ensure quality care prevent them from trying creative ways to help their patients function better. However, at present we do not even have uniform standards for patient safety, safety in case of fire, and humane care. Such standards must consider the special disability of these individuals.

In conclusion, we have identified the enormous burden dementia places on families, and underscored the urgent need for respite. In addition, good care and good medical care can improve patient function, well being and quality of life.

Much remains to be done: we must encourage research into innovative patient care and into ways to deliver coordinated, effective services to victims and families. We must ensure quality and make access to care equitable. We must train care providers.

The recognition that there are things we can do now for victims of dementing illnesses makes it imperative that we make quality care available to them. How can we deny to 2 million people a kind of care we know how to give?

Like Dr. Martin Luther King, I have a dream. The program I described to you was a model program and soon the team who put it together will no longer be in that facility. My dream is that we take what this team has learned and what other teams like them have learned as our model. Let us fund five centers in different regions of the country. Each center would offer care for three levels of patients, mildly impaired, moderately impaired, and severely impaired, and would experiment with short term inpatient respite and day care as well as residential care. Each of these centers would be linked to experts in health services delivery research so that we can document what works and how much it costs. And at each center, visiting service providers could learn the special techniques of care so that they could initiate them in their own facilities.

The legislation we are discussing to day sets the state for this dream.

Mr. WYDEN. We would thank you all. You have just been a superb panel in every respect. I think every member now has a better understanding of what this illness is all about.

I have very much appreciated your suggestions. Many of them have been practical, solid ideas, model programs, for example. Both my colleague from New Jersey and I have pointed out we haven't been able to get the administration to spend the funds that were allocated in the last Congress to set up regional centers. There is something very sad, it seems to me, about the budget proposal in this Congress where \$8.3 billion was requested for the Star Wars Research Program and yet we are cutting back funds for health care research.

I very much hope that because of your compelling testimony we can turn that situation around.

Mr. Plum has to leave, and I think all of the Members want his input. So a question or two for you, and I want to yield to Mr. Rinaldo and my other colleagues.

Mr. Plum, it seems to me that it is a given that nursing home care is almost inevitable for Alzheimer's patients, in some instances for 10 or more years. It would seem to me that the Medicaid costs for the States as a result of this would go up astronomically.

We have gotten estimates, from the committee staff that Medicaid costs would go up 5 to 10 billion dollars as a result of the need for additional services for Alzheimer's patients.

Is that your estimate, as well, or do the people associated with you have a different analysis?

Mr. PLUM. Congressman, I appreciate your earlier comment about the current administration's position in refusing to spend the dollars. The view is somehow that you can shift some of these issues back to the States and the States can come up with the resolution. I think you are correct in the kinds of numbers that you are using in terms of nursing home care costs, but the feeling that the States could alone pick that up is an unrealistic view.

Mr. WYDEN. One other question and then I am going to yield to my colleagues. We do want to confine questions just to Mr. Plum, because he has to depart.

I think one of the things, Mr. Plum, that Maria O'Brien really touched on is that it would be a service to alert citizens to their own risks, to the possibility that they may face Alzheimer's.

Is the State trying or are the States trying to focus on this area in particular? This strikes me as essential—an early warning system effort to try to prepare people to look to services that might help minimize the shock and the cost and the like.

Mr. PLUM. Well, I think Maria O'Brien and Jim Strong are to be commended for coming forth today and with the kind of film that will be on the television tonight, those other kind of public awareness programs are critically important.

The ADRDA, the association that has been formed to work with support groups and families, are playing a really key role in all this. They are out front of all levels of Government and quite frankly, the actions that are now coming from the States, come as a result of these citizen groups who are raising the level of awareness.

Raising the level of awareness is very critically important at this point in time. It is primarily on the back of the citizens, I think active involvement on the part of State and Federal Government to assist with this is also needed.

Mr. WYDEN. The gentleman from New Jersey.

Mr. RINALDO. I have no questions of Mr. Plum.

Mr. WYDEN. Mrs. Byron.

Mrs. BYRON. I feel that I should probably be on the other side of the table on this issue, having just 1 month ago today buried my father of who suffered from Alzheimer's disease.

This is an issue of which I think the American public is becoming more aware. I think the enormous amount of input that we have seen from support groups, such as yours, has been an immense help. I know from a personal experience the difficulty of sitting here in Washington, while he lived in Santa Barbara, CA, and trying to be of assistance to my family in managing the enormous number of stumbling blocks that come on a daily basis, and yet, at

the same time, trying to continue with what I am suppose to be doing here.

And yet, the more aware we become, the much more understanding we become. I would like to congratulate each and every one of you for the testimony that you have given today and say that I can identify extremely well with the issues that you have talked about today. I am wholly supportive of the mission that you have.

Mr. WYDEN. Thank you, Mrs. Byron.

Would any other Member like to ask some questions of Mr. Plum?

Mr. WISE. Mr. Plum, as one who also represents a rural State, I wanted to ask you if you had any thoughts as States put together concepts such as you have done in the State of Virginia, I represent West Virginia, whether there is anything that ought to be taken into consideration as far as rural areas go? Do you see in your experience perhaps it is even more difficult to get some of the services to people?

Mr. PLUM. Yes, sir, Congressman, I must admit to you that in Virginia we are trying to get a handle on that and a series of associated problems. We set up a study commission but what I have noted here in the very expert testimony we received from the witnesses, I think we want to follow up taking a look at some of the model programs that have been described here.

That is in part the problem. There is no clearinghouse that I am aware of that kind of puts together that information that we can draw upon so that when the Virginia study goes forth or the California study goes forth, or other states take a look at the matter, and West Virginia as well, how we might draw on the experiences of others in terms of building model programs.

Mr. WISE. That is an excellent suggestion.

Mr. WYDEN. Do other Members have questions for Mr. Plum?

Let me begin then with other witnesses. We thank you, Mr. Plum, for coming.

A question to start with for you, Mr. Strong. What is the cost of caring for your mother? I gather she is now in the early stages of Alzheimer's.

Mr. STRONG. Yes, sir. Going from where she was, which was living in her own mobile home, which was paid off, expenses now are about \$33,000 more a year for the combined services of the independent care facility and the privately and separately hired nurses I have.

Mr. WYDEN. What part of the cost has been covered by private medical insurance?

Mr. STRONG. None.

Mr. WYDEN. How about Medicare or Medicaid?

Mr. STRONG. No, there hasn't been any.

Mr. WYDEN. State and local government?

Mr. STRONG. No.

Mr. WYDEN. So you are paying for it all yourself?

Mr. STRONG. Yes.

Mr. WYDEN. And have you exhausted her resources already?

Mr. STRONG. Not yet. And I tell you that is one of the things that I fear the most. There is one nursing home with an Alzheimer's wing in our community. They require the ability to pay for 2 years

of care to be admitted. Then you are guaranteed a Medicaid bed in that specialized facility. That is about \$60,000.

So I fear that I might be forced to admit her to a nursing home on financial grounds rather than grounds of medical need just to be able to assure her of long-term care in a good facility.

Mr. WYDEN. The reason I asked, is because it touches on a point that Ms. Mace made. That is, because of these huge costs, it seems to me that people are in effect having in some way to spend down on their resources, or exhaust them, in order to receive assistance from the Government under Medicare. Is that right?

Ms. MACE. That is the experience of many, many families. Part of the problem is that you spend down in order to become eligible for care and then at that point the nursing homes really don't want these patients, so you cannot get somebody placed.

Mr. WYDEN. What you are saying is that millions of Alzheimer's patients are just likely to fall between the cracks. There isn't going to be any way to pay for the care and services that they need.

Ms. MACE. Medicaid will pay for them, does pay for institutional care, but at very low rates, and the facilities are reluctant to take people who have spent down.

Mr. WYDEN. The only other question I had is for Dr. Reifler. You talked about Medicare denials for Alzheimer's patients, and I gather that is getting more and more widespread. It is my understanding that Medicare will offer some benefits for mental health services, but since Alzheimer's is considered a medical problem of neurological origins, reimbursement is denied for that. Is that correct?

Dr. REIFLER. It gets confusing.

Mr. WYDEN. Please enlighten us.

Dr. REIFLER. I don't know if I can enlighten anybody better than you just did, but I think what happened in the past is that the Medicare rules were simply not interpreted in a fair way and in the patient's best interest. I think that the Secretary's Task Force on Alzheimer's Disease has helped. I think it is clarified that in fact regardless of who provides the service, and I think really any physician who is informed and interested is capable of providing the services.

I think we should look at Alzheimer's as a brain disorder with primarily behavioral—

Mr. WYDEN. Tell us then, since this will affect millions of patients, how do patients and their doctors file for Medicare reimbursement today? What do they describe the illness as?

Dr. REIFLER. Well, at least in theory we should be able to write down the code number for Alzheimer's disease, and that should be reimbursed.

Now, again I said I think the task force has helped but when I called our own office last fall to find out if the word had gotten down, the explanation they gave to me was that well, if a patient with Alzheimer's had a broken leg they certainly would be happy to pay for services related to the broken leg. So I think that really the Secretary's intent has not been interpreted as she had intended, although I must say that the number of claims that people bring in to me that have absurd explanations, seems to be decreasing.

We haven't solved the problem yet.

Mr. WYDEN. The gentleman from New Jersey.

Mr. RINALDO. Thank you very much, Mr. Chairman.

I would like to ask Maria O'Brien a question. Suppose you were to meet someone today with a relative just recently starting the long decline of Alzheimer's. Looking at it from your own experience as the daughter of someone who had Alzheimer's, what would you tell them, what advice would you give?

Ms. O'BRIEN. The first advice I would give them would be to get in touch with the local chapter of the ADRDA, because they are truly a helpful supportive organization. They are an information resource and they can refer you to doctors, to kinds of care, they can refer the families and the caregivers to support groups that will help them emotionally bolster themselves for this long, arduous path they are about to take, and then I would tell them if they could possibly find a way to keep the person at home as long as possible, considering that they weren't combative or difficult physically to handle, that that would be probably financially a little bit easier for them if the family can share the burden and employ some sort of custodial care alternate.

That sort of pattern until financially they are in such decline they must institutionalize.

Mr. RINALDO. You left out physicians. Did you find physicians very helpful to you when they treated your father?

Ms. O'BRIEN. I find the physicians are beginning to be very sensitive to the issue, and psychologists, because really what falls on their shoulders besides diagnosis is the care for the people who are caring for the victim. So they are very sensitive to it. I don't think in just from my own personal experience, that basic physicians have a well-rounded knowledge of the problem. You basically are told you go take your parents or your wife home and take care of them, watch them like a toddler because they need to be supervised.

Mr. RINALDO. When your father first contracted this disease, did the physician, the treating physician, diagnose it properly and did he explain the diagnosis?

Ms. O'BRIEN. Well, my dad I think had been suffering, had been suffering seriously from Alzheimer's disease for maybe 5 years. It was only 2½ years ago that I saw on a piece of paper acute Alzheimer's disease, and earlier than that his general physician had stated that he had some sort of OBS, which is a sort of umbrella term for brain syndrome, which is any number of dementia problems.

Mr. RINALDO. Thank you very much.

I know there is a vote on the floor, Mr. Chairman.

Mr. WYDEN. Why don't we take a 10-minute recess to go attend to this vote. As the gentleman from New Jersey didn't have his full 5 minutes, we will start with him and proceed with all the members. With the indulgence of our witnesses we will be right back.

[Short recess.]

Mr. WYDEN. The committee will come to order. We apologize for the delay. Let us have the gentleman from New Jersey finish his questions, then we will go to our additional panel member, Mr. Lamden, who has arrived.

The gentleman from New Jersey.

Mr. RINALDO. Dr. Reifler, I know investigations of Alzheimer's have gone in at least four different directions, biochemical studies, trace metal studies, genetics, and latent or slow virus. In your opinion, has any research direction yielded more compelling results than others?

And the second part of my question is: would you say today that we are any closer to understanding more about the causes of Alzheimer's.

Dr. REIFLER. Yes, sir, without question I think that I still must say that we don't have a cure for Alzheimer's disease but we know much more about the basic chemistry.

Of the things that you mentioned, I think the biochemical research has been the most compelling. In the late 1970's, several laboratories independently arrived at the same conclusion, there was a deficiency of a specific chemical, acetylcholine, in the brains of patients with Alzheimer's disease.

Now there are several things that we might do to try to enhance the missing chemical. We might give something in theory the body could convert into acetylcholine. Two things you could buy at the health food store in theory might help, lecithin and choline. In fact, we haven't figured out how to do it. Maybe we have to give them in combination with something else.

There are other drugs that we can give that either fool the brain into thinking we have given it acetylcholine or that allow more acetylcholine to remain at the site of action.

So I think that there is very encouraging evidence. When this first time came out we hoped we would have a situation similar to Parkinson's disease where we found the drug that could replace the missing chemical. We haven't figured out how to do it, but I think that is a step that holds enormous promise and my prediction is that in the next decade we will come up with a major advance in therapy. Not a cure, but a major advance in therapy.

Mr. RINALDO. Thank you very much.

I have no further questions.

The CHAIRMAN. Mr. Bilirakis.

Mr. BILIRAKIS. Thank you very much.

I don't think I will take unduly long. I do have an opening statement I would like to have inserted in the record.

The CHAIRMAN. Without objection.

[The following was received for the record:]

PREPARED STATEMENT OF REPRESENTATIVE MICHAEL BILIRAKIS

Mr. Chairman, I would first like to thank you for the opportunity to be here today. Since I am no longer a member of the Aging Committee, I appreciate your kindness in allowing me to participate in this hearing. I would also like to thank the distinguished members of this panel for their indulgence.

I will keep my remarks brief, but I could not begin discussing Alzheimer's disease without discussing my district along the gulf coast of Florida. Mr. Chairman, approximately 50 percent of my district consists of retired Americans, who have worked long and hard in order to enjoy their senior years. Many have retired to my district in hopes of enjoying the company of friends and family and in hopes of leading an active and full retired life.

If you have ever witnessed the debilitating nature of Alzheimer's disease—and its effect on victims and their families—you can understand why we must seek ways to care for victims and provide assistance to their families. The disease creeps into a

person's life, like a thief in the night, stealing some of life's most precious moments, and robbing a victim of his or her well-deserved senior years.

The effect of Alzheimer's Disease on a victim's family only magnifies the tragedy. Family members are not only denied the active companionship of a loved one, but they face great emotional and financial burdens. Indeed, the families of Alzheimer's Disease patients become victims too, constantly facing the "36 hour Day" with little outside assistance.

In terms of caring for Alzheimer's victims, I would first like to mention a program in my district which I think has provided tremendous assistance to victims and their families—although I consider this program just a beginning in our efforts to alleviate the devastating effects of this disease. Under the guidance of Dr. Eric Pfeiffer at the University of South Florida Gerontology Center, family support groups have been organized throughout the Tampa Bay area. These groups provide information on the disease and legal, financial, and social counseling for the family.

I praise this initiative, not only for the effective work that I have witnessed, but because this approach to care centers on the person and the family unit and is administered on a local level. The program involves the local community in a serious health problem and provides a most valuable service without the layers of bureaucracy and administration that could be involved. It is, in a real sense, people helping people.

But let me say also—that I think we need more, much more, in terms of delivering care to Alzheimer's victims. The problem is immense, as everyone in this hearing room knows, and a solution to caring for Alzheimer's victims will take a broad-based effort involving federal, state and local resources.

In this regard, I would mention two bills which I have introduced and which I like to term the "Alzheimer's Relief Package." Mr. Chairman, you joined me as a co-introducer and I appreciate it.

The first bill, H.R. 66, promotes the establishment of a national network of support groups for victims and their families. The intent of this bill is to duplicate some of the work of the Tampa Bay support groups on national level. It is my hope that this legislation, if enacted, would provide a forum for victims and their families in which they could speak to others who have had similar experiences. The support groups would be established in medical centers and other health care facilities which are receiving funds for Alzheimer's research and I believe they would provide a very valuable and necessary service. As I stated above, I believe we must direct our resources to the local community and the families which confront the horrors of Alzheimer's Disease. H.R. 66 would aid this effort across the country.

The second bill I have introduced, H.R. 67, is called the Alzheimer's Demonstration Projects for Medicare bill. This legislation mandates the Secretary of Health and Human Services to conduct ten demonstration projects in order to determine the feasibility of providing for alternative benefits under Medicare for those diagnosed as suffering from Alzheimer's Disease.

As you may know, demonstration projects were utilized in gaining approval of Medicare benefits for hospice care and I believe this approach will provide the necessary data and information needed to assess the feasibility of including Alzheimer's care under Medicare. I am presently in the process of obtaining cost estimates for this legislation and I believe it is necessary to move cautiously and deliberately to analyze all the ramifications of including Alzheimer's Disease under Medicare—but I believe it is imperative that we make a start down this road and that demonstration projects are the proper vehicle.

Mr. Chairman, I want to thank you once again for allowing me the opportunity to take part in this hearing. Today, I have mentioned legislation that I introduced, but I welcome all ideas and proposed solutions to the problem of Alzheimer's Disease in this country. I have seen with my own eyes too many victims and families torn apart by this disease and I feel it is clear that the time has come for action. We must continue the programs and research that has been initiated on Alzheimer's while constantly searching for new ideas and programs of care.

Alzheimer's disease is a terrible fact in our society and we, as a human and caring people, cannot afford to ignore its effect on our nation.

Mr. LIRAKIS. I would certainly like to say what I know everybody in the room felt, and that was the powerfulness of the film that we saw. Hopefully most of America will be watching the very sad film this evening. I think that film alone will probably do more for awareness and understanding than all of these hearings combined that we have had in the last 2½ years.

I might add that Chairman Roybal has been very much involved in this and has joined with me in a couple of bills, H.R. 66 and H.R. 67, that we have introduced to address this problem.

Mr. Plum also mentioned the need for a central clearinghouse to coordinate and communicate various States progress. I would hope that all of us feel that is a good idea.

I suppose we can talk about the funding and yes, that is necessary, and the research too, but maybe I should go back to Dr. Reifler very quickly, and to backtrack on the gentleman from New Jersey's questions about physicians.

Do we find, Doctor, in the medical schools, and in the residency periods that the medical profession is, in fact, acquiring more knowledge about this dreaded disease?

Dr. REIFLER. Yes sir, the medical profession is acquiring more knowledge. My own perception is that there is an enormous interest on the part of the medical profession in Alzheimer's, but, of course, I only go places where they are interested in hearing about Alzheimer's. So I think in practical terms I would have to say that it is mixed. There are a great many physicians who seek to inform themselves on the disease. Continuing Medical Educational Programs are consistently sold out on Alzheimer disease.

My wonder, my fear, is that perhaps we are preaching to the converted. Perhaps what we are doing is educating the physicians who are expressing a clear interest in it. There may be a lot of people that we are not reaching.

Mr. BILIRAKIS. Do you have an opportunity to take a look at some of the medical school curriculums to see that they are inserting this into the course of study?

Dr. REIFLER. Yes, sir, I do. I serve on a review committee for NIMH. We reviewed training grant applications and many of these training grant applications had very substantial components on training for Alzheimer's disease. Again, I think we have reason to be encouraged, but we are like the explorer who gets to the crest of the hill, then you have a mountain range on the other side. So I think we are at the crest of the hill, but we are just beginning to figure out what it is going to take to get over that mountain range.

Mr. BILIRAKIS. Mr. Strong, what part of Florida did your mother live in?

Mr. STRONG. She lived in the town of North Port, south of Venice.

Mr. BILIRAKIS. I see. Not in my district.

I do have approximately 50 percent retirees in my district, so this is a very prevalent thing down in that area. Was she diagnosed as having had Alzheimer's by the Florida doctor?

Mr. STRONG. No, she was diagnosed in Michigan during hospitalization for another acute episode. That began the investigation that led to the diagnosis. I should say—and I am sure it is true in your district as well as where she lived—she got along for some time living alone, because her neighbors were extraordinarily generous with their time and their caring, and I am sure that many, many of your constituents are in some way or another taking care of Alzheimer patients.

Mr. BILIRAKIS. Yes, I think that is very true. Thanks for making that point.

Doctor, you have heard how the diagnosis of Mrs. Strong was sort of a byproduct of having her in for care for something else. Now, under the current DRG system, would that have taken place? Would she have been conceivably diagnosed?

Dr. REIFLER. It is difficult, I know. I think what happens in an individual case with an individual patient, I think it is very difficult to predict. I think the regulations—I would be less than honest if I didn't say they can be confusing at times and sometimes it is difficult to know how a given diagnosis will be interpreted when it crosses the deck of the intermediary.

Mr. WYDEN. Would you yield?

Mr. BILIRAKIS. Yes.

Mr. WYDEN. It comes back again to the question I asked earlier. I think there are 467 categories of DRG's. If a family and physician wanted to get reimbursements for Alzheimer under DRG's, which one of the categories would they use?

Dr. REIFLER. Well, again what I said earlier, there are two categories for Alzheimer's disease, one is listed as a neurological disorder and one is listed as a mental disorder. My understanding of the current regulations are that the Secretary has instructed the intermediaries that the diagnosis should be reimbursed regardless of which code is used. But I don't know that I am the best person to try to answer that question.

Mr. WYDEN. I appreciate the gentleman yielding.

Mr. BILIRAKIS. The point I was trying to make, in addition to that very important one, is the fact that under the DRG system basically you are admitted into the hospital for care for one particular type of a problem and if another problem is found, or even suspected, that first one is taken care of, the person is discharged, and then her to be readmitted to treat the second problem.

So I wonder, under the DRG system, whether your mother would have been diagnosed early enough in the game or as early in the game as she was under that system? That is an answer I think that we have got to come to when we review the overall DRG system, in addition to these other points.

Mr. STRONG. May I make a comment about DRG? My Mom was admitted to an acute care hospital when I was in Washington a couple of weeks ago for a national ADRA meeting. She had become nervous, and that had led to a dehydration condition that heightened her dementia.

She was discharged from the hospital, not really rehydrated because they were not able to keep an IV in her except when I had a private nurse in there sitting with her in the hospital, and they weren't able to get her to cooperate in drinking the berium for an upper GI, so because the time ran out, essentially she was discharged, untreated, and undiagnosed.

Mr. BILIRAKIS. That concerns me greatly.

Thank you, Mr. Chairman.

Mr. WYDEN. Would the gentleman from Pennsylvania like to ask some questions?

Mr. RIDGE. Yes, thank you, Mr. Chairman.

Mr. Strong, if I might ask you again, based on your personal experience, and perhaps the other panelists, as well, might want to respond, as we look toward some kind of legislative help beyond

the legislation around which this hearing is centered, but looking for something either in terms of a tax credit or a deduction for nursing care, or domiciliary care, or something hands-on, something also more concrete, it would be important for us to recognize that we won't be able to come up with a comprehensive package. It is unlikely, given the state of affairs here, that we will come up with a complete package to address every single physical, medical, and economic need.

Based on your experience, if Congress were to take that first step, or the first two steps, based on what you have to provide for your mother and other members of your family, what would be the single or the top two more important areas of direct hands-on assistance that we could provide to help you and help others to take care of their parents?

Mr. STRONG. Clearly, respite care and day care, and not just any respite care and day care, but models that are appropriate. Perhaps nonmedical models that are less expensive but provided by people who are skilled. I have never done it, but I am told if you have tried to give a bath to a combative Alzheimer patient, you will get a whole new definition of what skilled care is, and it is that kind of skill that is very rare and needs to be encouraged and made available in the form of in-home respite and day care.

Mr. RIDGE. Doctor?

Dr. REIFLER. Yes; I would agree completely with Mr. Strong. These are the comments I hear from families day in and day out, week in and week out, the need for respite care and day care, which are clearly related to each other.

Mr. RIDGE. Likewise?

Ms. MACE. I strongly support those too. I think that coordination and cooperation and interchange amongst the professions at the on hands level. It is very fine amongst the scientists, but I mean among day care centers and the various service providers who are out there. I think that problem is so immense that we must talk about really pooling and coordinating and communicating there.

Mr. RIDGE. Ms. O'Brien, I don't know if the question was drawn on Mr. Strong and others with personal experiences to identify the one or two immediate, and perhaps from your personal experience the most helpful responses that Congress could provide regarding less treatment, and do you have any thoughts?

Ms. O'BRIEN. Yes. I concur with everyone else respite care is essential in the matter, and any kind of relief that people can get in that area is essential to their well-being, and I like the idea of a national sort of clearing house of information too, because a lot of people are misinformed about Alzheimer's disease and do things according to articles they read that aren't particularly clear pronouncements of findings. So I think that would be very healthy.

Mr. RIDGE. Thank you.

Doctor, if I might inquire whether or not professionals are satisfied—such as yourself—satisfied with the degree of or to the extent that the medical profession is going about informing its own membership about this disease in terms of ongoing education, not necessarily to be critical, but if you must, you must. It is clearly something that the technology, the research over the past couple of years has accelerated, we know more about it. We will continue to

learn. We have to continue to learn. Is that getting out? I have heard some stories here that—I think Ms. O'Brien mentioned it was diagnosed 15 years ago as OBS.

Ms. O'BRIEN. Only about 5 years ago.

Mr. RIDGE. But are you satisfied in terms of what the medical profession is doing?

Dr. REIFLER. I am encouraged but not satisfied. The evidence that I have to go on suggests that there is a great increase in interest in medical education on Alzheimer's. As I mentioned earlier, when I sat on the review panel earlier this year for training grant applications, I was very encouraged by components that dealt with education of medical students and residents and practicing physicians on Alzheimer's disease.

Courses, continuing medical education courses on Alzheimer's are consistently sold out, but there clearly remains an element of the medical community that has not informed itself on Alzheimer's disease and has not educated itself, and so I would have to respond by saying that I am encouraged but not satisfied.

Mr. RIDGE. Thank you.

Ms. Mace, one observation. I think it is probably as a result of your efforts and that of your organization that we have in a couple of the communication groups of children—individuals whose mothers and fathers and sisters and brothers, in fact, they have been meeting for 3 or 4 years—I think in certain respects they have been leading the medical community in terms of interest, and so together, I think, they are contributing to what everyone seems to think is an important first step, that is, the total education not only of those who are dealing with it but of the public in general.

Thank you, Mr. Chairman.

Mr. WYDEN. I thank the gentleman for his comments.

Here is our time situation. We have a vote on the floor of the House of Representatives now. Ms. O'Brien, as I understand it, you have only a couple of minutes left before you have to catch a plane. Is if there is anything else you would like to say to the committee, why feel free to do that, then we will go vote.

Mr. Lamden, welcome back. We look forward to your testimony.

Ms. O'Brien, is there anything you would like to add?

Ms. O'BRIEN. I would like to say that I am very encouraged, first of all, to see this meeting here today and to see the awareness that all of you ladies and gentlemen have about the situation, and for all of us just as private citizens to be able to voice a problem to sensitive ears is wonderful, and the first step in the long battle.

I want to reiterate what everyone else has said, which is, there is a great deal of help needed and as immediately as possible is the picture, and respite care and nursing home breaks and information that is proper.

Thank you all, we appreciate it very much.

Mr. WYDEN. Thank you. The committee very much admires your courage and your willingness to speak out. It seems to me because you have, we are a little bit closer to the goal of locating the cause and developing the cure. We are very appreciative that you would come.

With that, we will take another 10-minute recess and come back for Mr. Lamden. I know we will have some other questions for the other witnesses.

[A short recess was taken.]

Mr. WYDEN. The committee will come to order again. We apologize for the inconvenience and the delay.

Mr. Lamden, we have been looking forward to your testimony. In the interest of time, perhaps you might highlight some of the key concerns that are important to you and we will make a full prepared copy of your testimony a part of the record.

STATEMENT OF RICHARD LAMDEN, EXECUTIVE DIRECTOR, HANDMAKER JEWISH GERIATRIC CENTER, AND VICE PRESIDENT, AMERICAN ASSOCIATION OF HOMES FOR THE AGED, TUCSON, AZ

Mr. LAMDEN. Mr. Chairman, and members of the committee, I am Richard Lamden, executive director of Handmaker Jewish Geriatric Center in Tucson, AZ. I also serve as president of the Arizona Association of Homes for the Aging, a State affiliate of the American Association of Homes for the Aging, and as vice president of the association's executive board. I also chair the social responsibility and resident life division at AAHA. I commend you for your diligent work in this area.

AAHA represents over 2,600 nonprofit housing and health related facilities for the aging which serve approximately 500,000 elderly throughout the United States. AAHA represents a wide range of facilities that have been providing health care, housing, and community services, some of them for nearly a century.

Alzheimer's disease is the most frequent cause of institutionalization for long-term care in this country. It is estimated that about one-third of Alzheimer's disease patients reside in nursing homes, while the remaining two-thirds are being cared for in noninstitutional settings. More than half of those institutionalized in nursing homes in the United States suffer with this disease. The total cost to individual families is estimated at \$24 billion per year.

The Adult Day Health Services of Handmaker Jewish Geriatric Center offers a comprehensive program of services caring for persons in their homes. Its goal is to provide respite for caregivers and a supportive environment for patients. I will not take the time to go through some of the initial aspects of the development of the program. What I would tell you is that Adult Day Health Services evolved from a small day therapy and activity program in a skilled nursing facility to one which now serves 500 people out of two locations.

Many participants are eligible for service at no charge under title XX of the Social Act, others pay the full daily rate or an adjusted rate determined by their ability to pay and the availability of a United Way subsidy. Other funding is provided by contributions from participants and the community.

The full program currently offers health surveillance, individual and group counseling, physical, speech, occupational and music therapy, training in activities of daily living, educational and intel-

lectual activities, crafts, recreation, and leisure activities, field trips, nutritional guidance and a hot noon meal.

The protective care unit of Adult Day Health Services specifically addresses the needs of Alzheimer and related disease participants. This program was recently moved to a newly acquired facility. The move was brought about by the need for more space, since the demand for services for disoriented people is an ever increasing one.

While endeavoring to serve more participants, we are also cognizant of the need for appropriate staff ratios, small group activities, space usage, maintaining security and utilizing the supportive network of staff and family.

A participant's placement in the unit is determined initially by the center's social workers, after seeing the person in his or her home environment. Protective care might be recommended if the person exhibits marked disorientation, agitation, wanders away from home, or when a significant need for family respite is indicated. The staff consists of the director of Adult Day Health Services, a program coordinator, two activity aides and a nurse. Additionally, a social worker and social work students work with staff, participants and families.

About 20 clients are served during a typical day. Some are physically disabled and cannot walk or use the bathroom without aid. A napping area is available for patients who find the 6-hour day too long to manage.

Activities in the protective care unit concentrate on the individual abilities of clients, while recognizing their limitations. Participants play reality games, such as identifying objects, sounds, smells, tastes, and recalling names of places and past events. They also participate in the full gamut of day health activities whenever possible, allowing them to interact with others in the facility.

While the adult day health program provides welcome respite for caregivers, handling day-to-day strains brought about by a family member with Alzheimer's disease is still an ordeal. A weekly social worker-led support group is offered at the center, allowing family members to express feelings about the very difficult burden of caring for their impaired spouse or parent.

The mission of adult day health services of Handmaker Center is to maintain and improve the individual's total health, so he or she can remain a functioning member of the community for as long as possible.

The success of programs such as Handmaker's are indicative of the need for affordable care for the impaired members of our community's families. Without these programs, caregivers face the despair and the income drain of having to institutionalize their loved ones. With encouragement, training, and care, the program inspires participants to live their lives to the fullest.

We commend you for demonstrating your interest in Alzheimer's disease by introducing H.R. 2280. The Comprehensive Alzheimer's Assistance Research and Education Act of 1985, appropriately dubbed CARE, will go a long way in providing the necessary funds and supportive services that are required by Alzheimer's disease patients and their families.

The American Association of Homes for the Aging has also recognized the need to provide information and education to our members as well as those in the community where the need is greatest. In the past year AAHA has created an Alzheimer's disease network comprised of nearly 100 representatives of our facilities. These representatives will share information and resources as well as provide support for others participating in the network. In addition, AAHA has recently published a guide to caring for the mentally impaired elderly. The book is the result of a joint effort of a variety of professionals in the field and is designed to aid those who work with the confused elderly.

Our population is aging and our ability to provide necessary services to this group is essential. AAHA has identified Alzheimer's as an issue which deserves to be one of our Nation's highest priorities. We will continue to support the efforts of this committee in securing the necessary funding for these programs.

Thank you very much.

[The prepared statement of Mr. Lamden follows:]

PREPARED STATEMENT OF RICHARD S. LAMDEN, ON BEHALF OF THE AMERICAN ASSOCIATION OF HOMES FOR THE AGING

Mr. Chairman, and members of the Committee, I am Richard Lamden, Executive Director of Handmaker Jewish Geriatric Center in Tuscon, Arizona. I also serve as President of the Arizona Association of Homes for the Aging, a state affiliate of the American Association of Homes for the Aging (AAHA), and as Vice President on the Association's Executive Board. I also chair the Social Responsibility and Resident Life Division at AAHA. I am pleased to be here this afternoon to participate in this timely hearing on Alzheimer's disease. I commend you for your diligent work in this area and your commitment to helping those who suffer from Alzheimer's disease as well as the families and friends of these individuals.

AAHA represents over 2,600 nonprofit housing and health-related facilities for the aging which serve approximately 500,000 elderly throughout the United States. Over 75 percent of AAHA member homes are affiliated with religious organizations, while nearly all the remaining members are sponsored by private foundations, government agencies, unions, fraternal organizations and community groups.

AAHA represents a wide range of facilities that have been providing health care, housing and community services, some of them for nearly a century. Many of our facilities are providing services to victims of Alzheimer's disease, where a number of them serve as the site for family support group meetings. Patients are also being served in adult day care centers, where they are receiving meals and other support services.

Alzheimer's disease is the most frequent cause of institutionalization for long term care in this country. It is estimated that about one-third of Alzheimer's disease patients reside in nursing homes, while the remaining two-thirds are being cared for in non-institutional settings mainly in homes by families. Caring for Alzheimer's disease patients at home can be expensive, frustrating, physically and mentally exhausting and frightening.

More than half of those institutionalized in nursing homes in the U.S. suffer with this disease. Annually, nursing homes spend an estimated \$13 million on the cost of caring for Alzheimer's patients. Medicare does not cover the cost of custodial care, which many Alzheimer's patients require, and Medicaid will only cover those who have depleted all of their own resources. This leaves the bulk of the patients out in the cold. Many families spend their entire life savings caring for family members afflicted with this disease. The total cost to individual families is estimated at \$24 billion per year. By 1990 this figure could easily reach \$30 billion.

The Adult Day Health Services of Handmaker Jewish Geriatric Center offers a comprehensive program of services to families caring for persons in their homes. Its goal is to provide respite for caregivers and a supportive environment for patients.

Many participants are eligible for service at no charge under Title XX of the Social Security Act. Others pay the full daily rate or an adjusted rate determined by their ability to pay and the availability of a United Way subsidy. Other funding is provided by contributions from participants and the community.

The program went through a series of changes before it emerged in its present form. It was first funded in the late 1960's through a demonstration grant by the Committee on Economic Opportunity and located in donated space in hospitals. As the program grew, hospitals facing budget and space crunches began to ask the program to find space in other locations.

Some donated space did not meet physical specifications required of an adult day care facility under Title XX regulations. It also became obvious that programming was most effectively developed in sites used exclusively for adult day care and designed for impaired elderly.

The day health area in use at Handmaker is 5,000 square feet specifically designed and built to accommodate up to 70 participants per day. It includes a kitchen as well as large activity areas accessible to clients with wheelchairs.

Adult Day Health Services has evolved from a small day therapy and activity program in a skilled nursing facility, to one serving 500 people out of two centers.

The full program currently offers health surveillance; individual and group counseling; physical, speech, occupational and music therapy; training in activities of daily living; educational and intellectual activities; crafts; recreation; and leisure activities; field trips, nutritional guidance and a hot noon meal.

The protective care unit of Adult Day Health Services specifically addresses the needs of Alzheimer and related disease participants. This program was recently moved to a newly acquired facility. The move was brought about by the need for more space, since the demand for services for disoriented people is an ever increasing one.

While endeavoring to serve more participants, we are also cognizant of the need for appropriate staff ratios, small group activities, space usage, maintaining security and utilizing the supportive network of staff and family.

A participant's placement in the unit is determined initially by the Center's social workers, after seeing the person in his or her home environment. Protective care might be recommended if the person exhibits marked disorientation, agitation, wanders away from home, or when a significant need for family respite is indicated. The staff consists of the Director of Adult Day Health Services, a program coordinator, two activity aides and a nurse. Additionally, a social worker and social work students work with staff, participants and families.

About twenty clients are served during a typical day. Some are physically disabled and cannot walk or use the bathroom without aid. A napping area is available for patients who find the six-hour day too long to manage.

Activities in the Protective Care Unit concentrate on the individual abilities of clients, while recognizing their limitations. Participants play reality games, such as identifying objects, sounds, smells, tastes and recalling names, places and past events. They also participate in the full gamut of day health activities whenever possible, allowing them to interact with others in the facility.

While the adult day health program provides welcome respite for caregivers, handling day-to-day strains brought about by a family member with Alzheimer's disease is still an ordeal. A weekly social worker led support group is offered at the center, allowing family members to express feelings about the very difficult burden of caring for their impaired spouse or parent.

The mission of Adult Day Health Services of Handmaker Center is to maintain and improve the individual's total health, so he or she can remain a functioning member of the community for as long as possible.

The success of programs such as Handmaker's are indicative of the need for affordable care for the impaired members of our community's families. Without these programs, caregivers face the despair and the income drain of having to institutionalize their loved ones. With encouragement, training and care, the program inspires participants to live their lives to the fullest.

We commend you for demonstrating your interest in Alzheimer's disease by introducing H.R. 2280. The Comprehensive Alzheimer's Assistance Research and Education Act of 1985, appropriately dubbed CARE, will go a long way in providing the necessary funds and supportive services that are required by Alzheimer's disease patients and their families. CARE seeks to aid in the advancement of research and coordination of Alzheimer's programs and services. The bill also seeks to improve the relationship between state and federal government, increase funding for research, and most importantly will look at the role of Medicare and Medicaid in providing reimbursement for nursing home care, respite and home health care.

The national education program provided by the bill will serve to educate the public about the disease while helping others to cope more effectively with family members who are afflicted.

The American Association of Homes for the Aging has also recognized the need to provide information and education to our own members as well as those in the community where the need is greatest. In the past year AAHA has created an Alzheimer's disease network comprised of nearly 100 representatives of our facilities. These representatives will share information and resources as well as provide support for others participating in the network. In addition, AAHA has recently published a guide to caring for the mentally impaired elderly. The book is the result of a joint effort of a variety of professionals in the field and is designed to aid those who work with the confused elderly.

Our population is aging and our ability to provide necessary services to this group is essential. AAHA has identified Alzheimer's as an issue which deserves to be one of our nation's highest priorities. We will continue to support the efforts of the Committee in securing the necessary funding for these programs.

Mr. WYDEN. Thank you very much.

Just a couple of questions for you. Are there any Alzheimer's patients who enter nursing homes earlier than their needs would actually indicate because the family doesn't have the support services needed to continue caring for them at home?

Mr. LAMDEN. Yes. It is my belief that that is the case. Where programs exist that can provide either the respite or the day care services, as has been addressed previously, I think it does tend to forestall premature institutional care and we seem to feel that is indeed a trend.

Mr. WYDEN. Do you find that families of Alzheimer's patients have more difficulty getting their relative into a nursing home than other applicants?

Mr. LAMDEN. I think in those communities where Alzheimer's programs have been developed in the nursing homes, it is not a problem. I think, however, that in a generalized statement, yes, it probably is more difficult, because there is still so many things unknown and there is a fear of that unknown by some.

Mr. WYDEN. Would you say that it is generally a problem if the patient is applying under Medicaid?

Mr. LAMDEN. Since I come from a State that does not have a Medicaid program, I would be making an assumption. I think the assumption is true though.

Mr. WYDEN. As so many nursing home residents have Alzheimer's or other forms of dementia, how are nursing homes preparing for the special needs of these patients and their families? Here we are talking about staffing and staff training, special services, nursing home designs, those kinds of things.

Mr. LAMDEN. I think that we are seeing the evolvement of many more courses for staff, programs for staff, to educate them, for facility administrators to educate them again to the needs, to look to those individuals who have spent time and effort in the special design of facilities, and I think there is more attention being given to some of these areas.

I think staff training, upgrading of staff, increasing numbers of staff to deal with Alzheimer patients, is being addressed by a number of facilities. I think this is one approach that is being taken.

Mr. WYDEN. In conclusion, let me ask you a question. It seems to me that we have really touched on four areas today that are important.

One of them is research. The other is respite care. The other is educating health care providers, and the fourth is Medicare and

Medicaid. These four areas that kept coming up again and again as areas where Government can play a role, where the Government should try to assist.

Why don't we go down the line, starting with you Ms. Mace, in terms of your priority. Say that we have all four of those come up—research, respite care, education, and improving Medicare and Medicaid. If you were advising us, which would you say ought to be first, second, or third? Could you do that?

If you want to say they are all tied for first place, in a time of tight financial resources, I think that would be helpful to the committee.

Ms. MACE. I really wish I had a good answer for that. I truly don't know.

Dr. REIFLER. I think it is a little bit like the situation we had when I was a child, polio was an epidemic. I think that we certainly had to do something to care for the people who had the problem and we had institutions where there were people in iron lungs. We had to do something to try to solve the disease and we managed to do both.

I think if I were going to put my two top priorities, I would say research and respite care, but the others, it is a little like choosing among food, clothing, and shelter, and those would be my two top.

Mr. WYDEN. I want to make it clear that the committee is not interested in forcing those who have Alzheimer's to choose between basic needs. The basic request is trying to see in a time of limited resources which ought to be most stressed. Your answer is a thoughtful one.

Mr. Lamden.

Mr. LAMDEN. I would agree, I think it is very hard to prioritize. In my own opinion, the respite care issue and the day care issue as addressed by others earlier, is extraordinarily important, followed by the need to deal a little more in the area of research.

Mr. WYDEN. Mr. Strong.

Mr. STRONG. Respite care is clearly the least expensive, most direct way to reduce both the Government's expenditures on Medicaid for nursing home care and the direct personal and financial loss to caregivers.

Research is the best way to control long-term costs of this disease.

I think something that needs to be carried forward is the idea that there are programs here that are all looking at reducing what is spent on Alzheimer's disease by putting in an investment now.

Mr. WYDEN. That is a very thoughtful answer.

I don't have any further questions of the panel. I do want to convey the chairman's regrets. He apologizes for having to leave early. He had an important amendment in the Appropriations Committee. I think you know of his commitment. No one in the Congress has done more to fight for the rights of older people who have faced this horrendous set of medical problems, than Chairman Roybal. He is very much prepared to take this fight to this Congress to get good legislation passed.

I think you will also see the committee pushing hard in the days ahead to make sure the administration allocates the funds that we appropriated in the last Congress that have not been spent. In a

sense, it appears almost that these funds have been impounded as part of these budget reductions. So I think the fact that you have been here and have spoken out so vigorously and so well for the rights of those who are afflicted with Alzheimer's is really going to help us to move toward the goal of finding the cause and developing the cure. For that we congratulate you and look forward to working with you in the days ahead.

Thank you, and the committee is adjourned.

[Whereupon, at 4 p.m., the hearing was adjourned.]

APPENDIX 1

SUMMARY OF H.R. 2280—COMPREHENSIVE ALZHEIMER'S ASSISTANCE, RESEARCH, AND EDUCATION ACT OF 1985 (CARE)

PURPOSE

To provide improved care and assistance for Alzheimer's victims and their families.

SUMMARY

Alzheimer's disease is one of a number of degenerative neurological disorders that affect nearly 3 million middle age and elderly individuals. The symptoms of Alzheimer's disease and these related disorders (ARD) are primarily psychological in nature. They include worsening changes in personality, memory deterioration, disorientation, and impaired impulse control and judgment. As the disease progresses, changes in intellectual functioning take place with even more severe changes. Victims may wander, develop erratic moods, become difficult to manage and incontinent with loss of bladder and bowel control. The disease eventually renders its victims helpless.

While Congress has directed much research towards the causes and care of these disorders, it has become apparent that the many issues involved in the research, treatment and management of these disorders have reached a point where a coordinated effort, including the states, the federal government and private groups, is warranted. A lag between the accumulation of knowledge about these disorders and dissemination to the medical community and public has resulted in misdiagnosis and lack of access to treatment management options for many patients. The nature of the disorder has left families with an extreme psychological, physical and economical burden that warrants a systematic examination of models of care and reimbursement policies.

Responding to the overwhelming need to assist the victims of Alzheimer's disease and related disorders, the CARE bill, developed in partnership with the Alzheimer's Disease and Related Disorder Association (ADRDA) and on behalf of its more than 120 Chapters nationwide, proposes the following initiatives: Establish a national educational program effort for ARD. Create model state programs encouraging the development of education and supportive services for Alzheimer's victims. Expand the program of research to identify the causes, prevention and treatment of ARD. Develop methods of service delivery that will promote the health and well-being of ARD's victims and their families by encouraging care in the home and reducing the stress on the families of patients with ARD. Increase training of health care professionals and para-professionals to improve the diagnosis, treatment and management of ARD.

PROVISIONS

State Alzheimer's programs.—A joint federal and state effort to develop services and policies to assist victims of ARD and their families is created. Initially, up to ten States receive grants to create State Alzheimer's Programs.

Develop diagnostic, treatment, care management, legal counseling, and educational services to care providers, victims, and their families. Make available respite care services for the ARD patient. (Up to 25% of the grant may be used for this purpose.)

Review state policies on the financing and reimbursement of the costs of health care for patients with ARD and identifying other policy changes that would improve the care of patients with ARD.

Disseminate information to victims, their families, health care providers, organizations established for patients with ARD and to the general public on services available to ARD patients.

Make grants available for 3 years initially and subject to an annual evaluation by the Department of Health and Human Services.

National Alzheimer's Education Program.—A national program is established (similar to the successful National High Blood Pressure Education Program) that creates a national focus on the problem of Alzheimer's and the care of its victims.

Brings together public and private organizations to develop better ways to provide care to Alzheimer's patients and assist their families.

Provides technical assistance to public and private organizations delivering services to Alzheimer's patients and providing information to the public and health care providers.

Establishes an Information Clearinghouse to collect information from research and treatment programs and makes this information available to health care professionals, professional organizations and the general public.

Foster and coordinate research, training, and education programs relating to the cause, treatment and diagnosis of ARD.

Medicare and Medicaid demonstration projects.—In order to use Medicare and Medicaid to provide better financial assistance to Alzheimer's victims, the Department of Health and Human Services is mandated to conduct Alzheimer's related research, demonstrations, and waiver projects including at least the following:

Coverage of alternative methods of health care for ARD patients including services designed to maintain the patient in the home.

Coverage of nursing home care. (Current reimbursement policy precludes reimbursement by Medicare until medical management of the condition is warranted, or by Medicaid until the financial resources of the victim are depleted.)

Appropriate reimbursement levels for nursing homes with ARD patients.

Research on Alzheimer's disease and related disorders.—The Department of Health and Human Services is required to develop a plan of Alzheimer's related research and to implement it through the National Institutes of Health, the National Institute on Aging, and the National Institute of Mental Health.

Extend the current Centers program by allowing for an increase in the number of Alzheimer's Centers to 20. These are to be administered by the National Institute on Aging in collaboration with NIMH, NINCDS and NIAID. The responsibilities of the Centers include: Conduct research into cause, prevention, diagnosis, treatment and management of ARD. Train health care personnel. Disseminate clinical information. Coordinate with other Centers and related public/private facilities.

Make additional grants for applied research related to ARD including: Research on family stress management and the development of health care and social support systems.

Increase training of researchers in the related specialty areas.

APPENDIX 2

TESTIMONY OF THE HONORABLE ARTHUR S. FLEMMING ON BEHALF OF THE AMERICAN PSYCHOLOGICAL ASSOCIATION AND THE ACTION COMMITTEE TO IMPLEMENT THE 1981 WHITE HOUSE CONFERENCE ON AGING MENTAL HEALTH RECOMMENDATIONS

The American Psychological Association and the Action Committee to Implement the 1981 White House Conference on Aging Mental Health Recommendations are pleased to have the opportunity to present this statement for the record on the Select Committee's hearing on "Caring for America's Alzheimer's Victims." We want to commend the Members of the Committee for their dedication to this extremely important issue. The APA and the Action Committee support H.R. 2280—"Comprehensive Alzheimer's Assistance, Research, and Education Act of 1985"—which bears the appropriate acronym of CARE. We believe that the federal government needs to play a larger role in caring for the 2.5 million Americans with Alzheimer's disease, and their families.

APA and the Action Committee believe the current federal role does not assure adequate health care services for persons with Alzheimer's disease. Our statement will focus on the failure of the Medicare and Medicaid programs to adequately provide for the health and mental health care needs of the victims of this disease.

Twenty years ago the federal government designed the Medicare system to provide for the health care needs of the over-65 population. Currently, it provides health care benefits for over 27 million elderly and 3 million disabled persons across the country at a cost of \$66 billion in FY 1984. Alzheimer's patients, however, because they do not neatly fit the Medicare biomedically-oriented model of care often "slip through the cracks" in terms of adequate care.

Alzheimer's disease is classified as both a neurologic and mental disorder. Most often, however, it falls in the mental disorder classification, and persons with Alzheimer's receive only limited benefits. Medicare mental health benefits are extremely limited. All out-patient treatment for mental and nervous disorders is restricted to an annual reimbursement ceiling of \$250, and the patient is required to contribute a 50% co-payment (compared to 20% for physical health care). The in-patient mental health benefit is also restricted to a lifetime maximum of 190 days.

Medicare's entire service delivery model also limits direct reimbursement only to physicians and insists, with limited exceptions, that all services be delivered or supervised by a physician. In the case of care for mental and nervous disorders, this is unrealistic and economically unwise as there are a large number of other mental health professionals—such as psychologists, social workers and psychiatric nurse specialists—who are qualified to provide care. Because of these limitations on mental health care, few appropriate services are available to Alzheimer patients.

In September 1984, the Health Care Financing Administration reversed a standing Medicare policy in order to permit Alzheimer's victims to receive some treatment for their disorder—without being subject to the mental health benefit limitations. This change addresses the "medical management" of the disorder and permits reimbursement for out-patient physician visits in connection with the neurologic aspect of Alzheimer's. This policy still ignores the greater problems surrounding access to mental health care that are often required during the long and debilitating course of a disease that is characteristic of Alzheimer's. It can only be viewed as a partial step toward meeting the health care needs of these patients for their "mental, psychoneurotic and personality" disorder.

The acute-care focus of the Medicare program contributes to its lack of provision of appropriate services for persons with Alzheimer's disease. In addition, Medicare does not encourage the use of institutional alternatives that could have positive implications for the financing system. Respite care and adult day care are examples of services that would not only help to relieve some of the emotional burden on caregivers, but lessen the burden on the financing system by helping to avoid—or at least postpone—the often necessary residential care. The data on the physical and

emotional toll experienced by caregivers of Alzheimer's victims indicates that over 50% suffer from significant depression, and underscores the need for these additional services, as well as for better mental health benefits.

Due to the long and debilitating course of the disease and the extraordinary toll taken on the caregivers, many Alzheimer's patients must eventually be placed in nursing homes. Medicare places benefit limitations on care through skilled nursing facilities (SNFs). Eligibility requirements for SNF care require that the patient enter the facility following a hospital stay. They must need skilled nursing care or rehabilitative services, and placement must be for the condition which treatment was given during hospitalization.

When these criteria are met, a total of 80 days of nursing home reimbursement is provided; \$50 per day co-payment is required between the 21st and the 80th day. After these benefits are exhausted, the patient must either make personal payments (which account for 44% of all nursing home payments), rely on private long term care insurance (less than 1% of all nursing home payments are from private health insurance sources), "spend down" to meet Medicaid criteria (if coverage is available), or be discharged to the care of family or friends.

Intermediate Care Facilities (ICFs) are the more usual nursing home placement for Alzheimer's patients. Reimbursement for ICF care is not covered by Medicare. Although it is not a federally-mandated service, most states have opted to offer some type of ICF reimbursement.

Medicaid—a joint federal/state welfare program, is the largest single source of financing for nursing home care, representing over 48% of all nursing home payments (a total of \$13.2 billion in FY 1982). It has been estimated that as many as one-half of nursing home residents have Alzheimer's disease or a related disorder, and that the care of these residents costs almost \$16 billion per year for their care.

Since Medicaid is a welfare program, an Alzheimer's victim must attain a state of poverty to qualify for this type of institutional care. The need for care, itself, is not a prerequisite for eligibility. At least one-half of Medicaid nursing home recipients were not initially poor upon entering the institutional setting, but had to "spend down" to meet state Medicaid eligibility levels. Alzheimer's extended disease course increases the likelihood that patients will exhaust their personal resources and become dependent on state Medicaid programs. The failure of the Medicare system to address the long-term care needs of our nation's elderly will continue to "pauperize" Alzheimer's and other patients with chronic disorders.

A recent clarification of the criteria used for making determination of "institutions for mental diseases" (IMDs) has allowed greater access to ICFs by Alzheimer's. ICFs are permitted to have up to, but not exceeding, 50% of their patient population diagnosed with mental disorders. Above this number the facility receives an IMD designation and Medicaid reimbursement is denied. A recent federal change removed Alzheimer's disease from this mental disorder quota, easing one of the barriers to Medicaid ICF placement. However, the situation remains problematic because other IMD criteria function to discourage treatment in ICFs for the mental health aspect of Alzheimer's. This is another example of how treatment may not be appropriately delivered because of the focus on the organic aspects of the disorder and inattention to the mental, behavioral, and emotional aspect of the Alzheimer condition.

The APA and the Action Committee extend our appreciation for this opportunity to present our views to clarify the extent of the Medicare and Medicaid reimbursement related to Alzheimer's disease. We hope that this statement will help to clarify any misconceptions that may have been raised during the hearing. We also hope that the Committee will continue to pursue the important issues surrounding the need for an increased federal role in the care of persons with Alzheimer's disease, and offer the assistance and expertise of our two organizations in this pursuit.

STATEMENT FOR THE RECORD BY MARGARET M. HECKLER, SECRETARY, DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. Chairman and Members of the Committee, thank you for this opportunity to share the views of the Department of Health and Human Services, and myself, about this devastating disease. My statement will focus on our research activities, on our efforts to assist the families of Alzheimer's disease victims to cope with and help their loved ones, and most importantly, the statement discusses what I believe to be one of the turning points in our battle with this terrible affliction.

RESEARCH HIGHLIGHTS

There is a scientific maxim in an area of great uncertainty such as Alzheimer's research. Looking across a vast field of inquiry, you plant the seeds of a hundred flowers, in the hope that some will fall on fertile soil and bloom. And so Alzheimer's research is being undertaken in many divergent areas and by many of the Department's research institutes, so that efforts will be fruitful.

Research that will bring improvements in diagnostic techniques, for example, is critical. Many treatable disorders mirror Alzheimer's, and the Alzheimer's diagnosis can only be made by a process of elimination, or *ex post facto*, through autopsy. But approximately 15-30 percent of Alzheimer's diagnoses are incorrect. This either inhibits treatment of other dementias or slows the necessary planning of long-term care for the Alzheimer's victim and his or her family.

Studies to determine genetic links continue, as well as inquiries into the possible roles of environmental toxins, such as aluminum. There is also research being undertaken to investigate a possible viral cause, and investigations into suggestions that the aging process may have an effect on the body's immune system.

The Public Health Service supported the research recently published in the *New England Journal of Medicine* that indicates a relationship may exist between Pick's disease and Alzheimer's. Antibodies that react to the pathologic microstructures of Alzheimer's, the "plaques and tangles", also react to Pick's bodies, which are the hallmark's of that disease. No such relationship, however, has been discovered with other brain disorders, such as Parkinson's and Huntington's diseases. The discovery of this link between the two diseases is yet another clue, another piece of the puzzle.

Funding for Alzheimer's research continues to accelerate at a rapid rate. In 1976, less than \$4 million was spent on Alzheimer's research. But in fiscal years 1983, 1984, and 1985 combined, more than \$100 million will have been spent in this area, with another \$49 million expected to be expended for Alzheimer's-related research in fiscal year 1986.

The Department is also undertaking several new activities. The National Institute on Aging will award an estimated total of \$6.6 million over the next two years for centers for excellence on Alzheimer's disease. These centers conduct multidisciplinary research, promote research training, and design ways to transfer information to the community. The five planned centers are in addition to the ones I announced last fall which are at Harvard University, the University of Southern California, Mt. Sinai School of Medicine, University of California at San Diego, and Johns Hopkins.

There is another promising avenue of research. It will occur in concert with an on-going, long-term study supported by the National Institute of Mental Health into the cause and cure of Alzheimer's, but it will address the problems which Alzheimer's victims and their families face on a daily basis. This marks yet another turning point in our exploration of the "undiscovered country" of Alzheimer's.

Memory loss and intellectual decline are the only constants in the clinical picture of Alzheimer's disease. We cannot yet prevent the disease, we cannot yet reverse its course, and we cannot yet stop its progression. But there are symptoms of this brain dysfunction that, although part of the Alzheimer's process, can be treated separately with medication and behavioral therapies. For Alzheimer's concomitant symptoms—such as the depression and delusions that make the dysfunction more acute and lower the quality of life—there are various interventions that can be employed.

When the weight of these "excess disabilities" is lifted the patient is able to function better and the family is better able to cope. The deterioration of the disease is not abated, but the rate of the decline is reduced and the quality of life is improved.

A case in point: An evaluation for a nursing home placement was requested for an 80 year old woman with Alzheimer's disease. The woman had been living alone in her apartment with a progressive loss of memory, and had done relatively well until she began to wander.

Her neighbors and apartment manager became concerned for her safety and an attempt was made to provide her with homemaker assistance, but she vehemently refused. A further evaluation was carried out, and in addition to the very noticeable memory dysfunction, it was discovered the woman was experiencing delusions that "someone was using force to interfere with her in her apartment."

A combination of family support and medical management, through the use of antipsychotic medication, helped get the delusions under control and enabled the woman to accept household help. This treatment did not affect her basic dementia. But it did allow the woman to stay in her apartment another two years, until her cognitive dysfunction became so acute that 24-hour-a-day nursing care became necessary.

George Bernard Shaw wrote that, "Life is a disease; and the only difference between one man and another is the stage of the disease at which he lives." For the Alzheimer's victim, their life does become their disease. Our challenge is to develop the best solutions to the unique problems of this progressive disease at each of its stages.

We can meet this challenge in three ways: By making sure that clinicians have access to the newest approaches to care; by including a focus on treatment of concomitant symptoms in the training of health professionals and caregivers; and by recommitting research efforts to study interventions to determine which, and in which combinations, they are most effective.

HELPING THE FAMILIES

At the heart of our attempts to improve the quality of life for the victims of this tragic disease, is the goal of keeping them in their homes, and not in institutions, for as long as possible. However, we recognize that this creates tremendous hardship and sacrifice on the family that lovingly cares for the Alzheimer's victim. There are several new initiatives in the area of social services which attempt to reduce this burden on families—

The National Institute of Mental Health will be awarding new grants for "research on family stress and the care of the Alzheimer's disease victim." Proposals for studies of the nature, consequences and interplay of stress on the individual and the family who provide at-home care, and the Alzheimer's disease patient, will be accepted beginning July 1, 1985. Some grants will be awarded this year. Additional grants will be awarded after November 1, 1985 and March 1, 1986.

The Administration on Aging will be awarding grants for proposals demonstrating new approaches to strengthen community support groups for Alzheimer's families. Grant awards will total \$750,000 and the recipients will be announced this summer.

To develop home health services, the Health Resources and Services Administration has established a \$2 million grants program and has made available \$1 million for training of home health paraprofessionals. Priority will be given to applicants establishing services in underserved, especially rural, areas.

And we are doubling our efforts to encourage volunteer respite care, to relieve the tremendous strain on the caregiver in the home. The Department's "Project Share" will release the first complete respite care manual at the end of this month. This "how to" guide is intended to instruct volunteer groups in ways to develop community respite care programs.

Also, as part of my secretarial initiative on respite care and to promote the best possible home care, we will distribute early this summer a brochure that further explores options for respite care in the community.

But even with these support systems, the cost of caring for the Alzheimer's disease victim, in both human and economic terms, is great. The sacrifices are not just physical and emotional, the financial consequences of Alzheimer's are devastating as well.

As announced last September, we have removed the \$250 limit on outpatient treatment for Alzheimer's patients under Medicare part B, by clarifying the classification of Alzheimer's as a brain disorder. Except for psychotherapy, the billing for care will be according to the nature of the physicians' services, not diagnostic code. This will correct an unintended inequity that affected a limited number of Alzheimer's disease victims. Through the Health Care Financing Administration [HCFA] we will continue to work to clarify these new regulations, and to facilitate their implementation.

To further evaluate the Federal role in financing, HCFA has solicited grant applications focusing on innovative, cost saving methods for the administration of Medicare and Medicaid. One long-term goal of this research is to enable beneficiaries to shop around for high-quality services. Awards totaling up to \$6 million will be issued by the fall.

Also, the Department has sponsored an independent study of private sector financing of long term care. In addition to analyzing current resources and options for feasible, cost-effective long-term care in the private sector, the study also identified barriers in the marketplace that could prevent widespread development of these mechanisms. However, specific areas that merit further study, such as private long-term care insurance, should be pursued by the private sector.

Finally, research into long-term care options, the Department's national long-term care channeling demonstration, is now nearing completion. This project was established to test how to best provide cost-effective alternatives in community-

based, long-term care delivery systems. The program will be evaluated according to criteria that include—whether channeling enables patients to live in the community rather than in institutions; whether channeling maintains reliance on informal supports and reduces the emotional and financial burden of care placed on families; and channeling's impact on the public and private costs of long-term care. Answers from this investigation and others may give us the answer to how much responsibility for Alzheimer's care the community can bear cost-effectively.

SUMMARY

It is imperative that while we have spread the seeds of research, hoping that a hundred flowers will grow, that we not rest waiting for the harvest. Until then, we must continue to encourage community support, alternative methods of financing and care, and, most importantly, encourage interventions into the "excess disabilities" of Alzheimer's victims. We must improve their quality of life now and offer new hope to a generation of older Americans yet to come.

PREPARED STATEMENT OF HON. JAMES R. THOMPSON, GOVERNOR, STATE OF ILLINOIS

In Illinois, approximately 111,000 persons are victims of Alzheimer's Disease. Because this incurable brain disease primarily affects the elderly, the Illinois Department on Aging has been and will continue to be active in addressing the needs of disease victims and their families.

Presently, the statewide Case Coordination Unit network provides a mechanism for Alzheimer's victims and their families to access Department on Aging services through local agencies. In addition, the statewide toll-free 800 line serves as a crisis response system, linking callers to appropriate agencies for needed assistance. This assistance can be provided through the Community Care Program, which offers chore, homemaker and adult day care services and can provide on-going, regular respite or assistance to families of Alzheimer's victims who are eligible for the program.

Another current effort of the Department on Aging involves the sponsorship of several Alzheimer's training seminars targeted for professionals in the aging and health networks, as well as families of Alzheimer's victims.

In fiscal year 1986, the Department on Aging will also take the lead in an Alzheimer's Initiative that will focus on the development and staffing of a multidisciplinary Task Force, implementation of research and demonstration projects, and a statewide conference. I have asked the General Assembly to approve a \$300,000 expenditure for this initiative.

A more detailed description of this effort is outlined below:

1. *Alzheimer's Task Force.*—The Department on Aging is establishing a 12-member multidisciplinary task force including health care professionals, nursing homes, social services, the Alzheimer's Disease and Related Disorder Association support groups, practitioners, institutions of higher education, family and other caregiver representation as well as four (4) state agencies: Department of Public Aid, Department of Public Health, Department of Rehabilitation Services and the Department of Mental Health and Developmental Disabilities. We know there are relatively few programs specifically designed for victims and families of Alzheimer victims. We know there are relatively few training initiatives for professional caregivers of Alzheimer victims. Therefore, the task force will be focusing on the following goals:

1. Evaluating the needs of Alzheimer's victims across the health care system;
2. Evaluating the present Long Term Care system and its adequacy to meet Alzheimer's victims' needs;
3. Re-evaluating current eligibility criteria, service packages, staff skills, training needs and to make recommendations to assure more complete coverage;
4. Coordinating interagency initiatives to improve the system;
5. Identifying needed legislation for programmatic issues related to Alzheimer's Disease in time for the FY87 budget process.

2. *Research and demonstration projects.*—Two demonstration projects, Respite Care and Companion Care services, are already underway at the Illinois Department on Aging. Both emphasize the development of services which are of special concern to families of Alzheimer's victims. A third project, the development of a specialized program of day support services for Alzheimer's victims within currently funded Adult Day Care programs, will be initiated in FY 86.

3. *Statewide Conference.*—In the Spring of FY86, the Department will sponsor a statewide conference on Alzheimers. The session will be structured to focus on:

1. Research advances in diagnosis and treatment of Alzheimer's Disease;

2. Best practice sessions on formal services for Alzheimer's victims; and,
3. Techniques/services of value to family caregivers of Alzheimer's victims, including development of social support groups.

Participants are expected to include academicians, service providers, and family caregivers. The Task Force will have a key role in developing sessions and identifying presenters.

In conclusion, I wish to emphasize that the Illinois General Assembly is also extremely supportive of efforts to aid Alzheimer's victims and their families, as indicated by twelve Alzheimer's bills that have been introduced during this legislative session.

